THE IMPORTANCE OF FACIAL APPEARANCE IN PATIENTS WITH EYE CANCER

& RESEARCH PORTFOLIO

Nicola J. Brown

(BSc Hons., MSc)

August 2002

Submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology, Department of Psychological Medicine, Faculty of Medicine, University of Glasgow.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

TABLE OF CONTENTS

PART ONE (this bound volume)

		Pages
1.	**Small Scale Service Evaluation Project** Waiting Times and Attendance / Non-attendance in an Adult Clinical Psychology Department.	**1-20**
2.	**Major Research Literature Review** A Systematic Review of Studies that have examined the Impact of Facial Appearance Change in Eye Cancer and Head and Neck Cancer Patients.	**21-67**
3.	**Major Research Project Proposal** The Importance of Facial Appearance in Patients with Eye Cancer.	**68-89**
4.	**Major Research Project Paper** The Importance of Facial Appearance in Patients with Eye Cancer.	**90-133**
5.	**Single Case Research Study (Abstract)** Targeting Self-esteem in the Treatment of Social Anxiety: A Single Case Experimental Design.	**134-136**

Appendices

1.	**Small Scale Service Evaluation Project**	**137-138**
1.1	Copy of Notes for Contributors to *Health Bulletin.*	138
2.	**Major Research Project Literature Review**	**139-142**
2.1	Copy of Notes for Contributors to *Psycho-Oncology.*	140-141
2.2	Observer-rated Disfigurement Scale.	142
3.	**Major Research Proposal**	**143-158**
3.1	Participant Information Sheet.	144
3.2	Participant Consent form.	145
3.3	Appearance Schemas Inventory (ASI).	146
3.4	Appearance Schemas Inventory-face (ASI-face).	147
3.5	Body Image Ideals Questionnaire (BIQ).	148-151
3.6	Body Image Ideals Questionnaire-face (BIQ-face).	152-153
3.7	Standard instructions for PRISM and PRISM+.	154-155
3.8	Clinician-rated Facial Appearance change scale.	156
3.9	Letter confirming ethical approval.	157-158
4.	**Major Research Project Paper**	**159-162**
4.1	Notes for Contributors to *Psycho-Oncology.*	160-161
4.2	Means and standard deviations for the Appearance Schemas Inventory (ASI) and the Body Image Ideals Questionnaire (BIQ).	162

PART TWO (Separately bound volume; numbered from page 1)

	Pages
Single Case Research Study	**1-27**
Targeting Self-esteem in the Treatment of Social Anxiety: A Single Case Experimental Design.	
Appendices	**28-32**
1. Notes for contributors to *Behavioural and Cognitive Psychotherapy.*	29-30
2. Brief-Fear of Negative Evaluation Scale (Brief-FNE).	31
3. Comparison of experimental conditions using ITSACORR.	32

Acknowledgements

Firstly, I would like to thank Dr Craig White for his guidance and support throughout the whole research process. From the course team I would also like to thank Drs Liz Campbell and Andrew Gumley for guidance on the single n research case. I am also grateful to Drs Charlie Marsh and Clare Parkinson for their proofreading skills and to Alf Gillham whose help with the database was invaluable on the small-scale research project. For their enthusiasm and interest in the project, I want to acknowledge Dr Ewan Kemp (Consultant Ophthalmologist) and his team, in particular his secretary Donna Tidy. Also, many, many thanks go to friends and family for agreeing to be control participants. Most of all though I want to thank Roger for his constant support and patience throughout this research process.

1. SMALL SCALE SERVICE EVALUATION PROJECT

Waiting Time and Attendance / Non-Attendance in an Adult Clinical Psychology Department

Prepared in accordance with the guidelines for submission to:

Health Bulletin

(See Appendix 1.1 for notes to contributors).

Waiting Time and Attendance / Non-Attendance in an Adult Clinical Psychology Department

Nicola J. Brown
Department of Psychological Medicine
University of Glasgow
Glasgow
G12 0XH.

Abstract

***Objectives*:** To establish the distribution of waiting times for a sample of referrals, and to determine the impact of waiting time on attendance and non-attendance.

***Design*:** Data in relation to time waiting for an appointment was retrieved from a departmental database. The rates of attendance and non-attendance were established in relation to waiting times, and further analyses made.

***Setting*:** A West of Scotland adult department of Clinical Psychology.

***Subjects*:** All patients who were referred in a one-year period (1-1-98 to 31-12-98), and who had also been discharged at the time of data collection (April 2000): n=513 (57% female). Age range 18-99 years (mean 37.7 years).

***Results*:** 341 (66.5%) referrals were Attenders (those who had attended at least one appointment), and 172 (33.5%) referrals were Non-Attenders (those who had never attended). The range of waiting times was 0-51 weeks for Attenders, and 2-51 weeks for Non-Attenders. An independent samples t-test showed that the mean waiting time for Non-Attenders (27.4 weeks) was significantly higher ($t=5.52$, $df=511$, two-tailed $p<0.01$) than that for Attenders (21.2 weeks).

***Conclusions*:** The hypothesis that a shorter waiting time would be associated with higher rate of attendance, and a longer waiting time with a decreased rate of attendance was supported. The rate of non-attendance was approximately 20% for those seen within 0-4 weeks, increasing to over 50% for those waiting 35 weeks or more. If, following an evaluation of a recently introduced opt-in system, this pattern of waiting time and attendance continued, it is recommended that the department consider providing additional support for patients waiting 35 weeks or more, in order to try and increase the rate of attendance at this time.

Introduction

Demand for clinical psychology services

The 1993 British Psychological Society, Division of Clinical Psychology report[1] described an NHS shortage of qualified clinical psychologists in the UK, coupled with a 20-100 per cent annual increase in demand for their services. At that time there were over 10,500 people waiting to see a clinical psychologist, with 44% of referrals being made to departments with waiting times of six months or longer. It is therefore not surprising that in the same survey only 15.5% of clinical psychologists felt that their services were meeting the demands made upon them. Conaghan *et al.*[2] described how clinical psychology departments across the country are still "wrestling" with the problems of how to manage resources in the year 2000.

Non-Attendance of therapy

In a service already struggling to meet demands, patients' failure to attend appointments therefore results in a substantial waste of precious resources. The rates of non-attendance that are reported vary, as do definitions of non-attendance, with some researchers using the term to refer to patients who fail to attend only their initial appointment. For the purposes of this study, non-attendance was defined as never attending an appointment, and recent studies carried out in UK clinical psychology departments using this definition have found non-attendance rates to be generally high. For example, Keen *et al.*[3] reported a non-attendance rate of 33% in their service in the East of Scotland, while Loumidis and Shropshire[4] reported an even higher rate of non-attendance of 52.6% in their service in the North of England.

Waiting Time and Non-Attendance

Waiting time is generally defined as the time elapsed between being referred and receiving an appointment. Researchers have generally found an association between waiting time and non-attendance. For example, Morton[5] found that non-attenders waited longer for an appointment than those who did attend. In addition, Loumidis and Shropshire[4] found that waiting for more than six months was associated with non-attendance, and patients who had not attended waited an average of six weeks longer than attenders. However, Weighill *et al.*[6] found that the interval time between referral and appointment was not related to non-attendance, although they did not specify how long patients had waited for an appointment.

Aims

- The first objective of the present study was to establish the distribution of waiting times for a one-year sample of referrals in a West of Scotland clinical psychology department.
- The second was to establish the impact of waiting time on the rates of attendance and non-attendance, and to determine whether waiting time was a significant factor in attendance in this department.

Hypothesis

- Based on findings that, generally, non-attendance *is* associated with a prolonged waiting time, it was hypothesised that a shorter waiting time would be associated with higher rate of attendance, and a longer waiting time would be associated with a decreased rate of attendance.

Method

Setting

The study was carried out in an adult Clinical Psychology department based in a psychiatric hospital in the West of Scotland. The department accepts both inpatient and outpatient referrals pertaining to patients residing in the catchment area. Clinics are held at both hospital and community sites. The department operates three categories of referral: Urgent, Priority and Routine (categorisation made according to allocation by the referrer). They aim to see all Urgent referrals within 0-3 weeks, and all Priority referrals within 9 weeks. Information is given to Routine patients explaining that their waiting time for an appointment will be approximately 20 weeks. The actual waiting time for Routine referrals depends primarily on how many Urgent and Priority referrals are waiting. Thus, it may be more or less than 20 weeks. Re-grading of categorisation rarely occurs (in less than 5% of cases), and only occurs if requested by the referrer.

Subjects

The sample comprised all patients who were referred in a one-year period (1-1-98 to 31-12-98), and who had also been discharged at the time of data collection (April 2000). Referrals had to relate to patients that had been discharged, as in this department, data regarding attendance is not entered onto the database until the point of patient discharge. It was not possible from the database to distinguish inpatients from outpatients. Although the issues with respect to waiting time would be different for these two groups, the overall proportion of inpatients in this sample was known to be small (less than 5%). Thus it was felt that including inpatients would not greatly affect the outcome, which would mainly reflect the outpatients' issues with respect to waiting time.

Procedure

For each referral, the following fields were selected from an existing departmental "Access" database, and a hard copy produced:

- Gender (male, female)
- Age at time of referral (in years)
- Category of referral (Routine, Priority, or Urgent)
- Date of referral
- Date of first appointment
- No. of appointments attended

The data were then entered manually into "Excel", and waiting time (in weeks) for each patient calculated from "Date of referral" to "Date of first appointment". Attendance data for each patient was assigned to one of two groups, "Attenders" (i.e. those who had attended at least one appointment), or "Non-Attenders" (i.e. those who had never attended with number of appointments attended equal to zero).

Results were analysed in terms of waiting times and attendance using the SPSS statistical software package, and are reported in the section below.

Results

The total number of referrals for the period 1-1-98 to 31-12-98 that were eligible for inclusion was **513** (57% female). There was a wide range of ages: 18-99 years (mean 37.7 years). Of the referrals, 341 (66.5%) were Attenders (247 Routine referrals, 54 Priority referrals, and 40

Urgent referrals), and 172 (33.5%) were Non-Attenders (144 Routine referrals, 22 Priority referrals, and 6 Urgent referrals).

The range and mean waiting times (in weeks) for Attenders and Non-Attenders are shown in Table 1.

INSERT TABLE 1 ABOUT HERE

Each waiting time was rounded to the nearest whole number, and then grouped into one of eleven five-week blocks of waiting time (five-week blocks were chosen as this best fitted the range of waiting times). The numbers of those attending, not attending, and the overall numbers for each of the eleven five-week blocks of waiting time are shown in Table 2. The distribution of waiting times according to referral category is shown in Figure 1.

INSERT TABLE 2 and FIGURE 1 ABOUT HERE

The relative percentages of attendance and non-attendance by patients, categorised according to block of waiting time, are shown in Figure 2.

INSERT FIGURE 2 ABOUT HERE

From Figure 2, it can be seen that as waiting time increases, the percentage of those attending decreases. An independent samples t-test was performed to determine if waiting time was significantly different between the groups. There were no missing values, and data from all 513 referrals were available for the analysis. The mean waiting time for Non-Attenders (27.4

weeks) was found to be significantly higher ($t=5.52$, $df=511$, two-tailed $p<0.01$) than that for Attenders (21.2 weeks).

Hence, the hypothesis that a shorter waiting time would be associated with higher rate of attendance, and a longer waiting time would be found to be associated with a decreased rate of attendance was supported.

Discussion

Distribution of Waiting Times

The first objective of this report was to obtain the distribution of waiting times for the sample. The overall range of waiting times was 0-51 weeks (see Table 1), and as can be seen from Figure 1, the modal waiting time was 20-24 weeks (n=104). A large number of patients (n=87) also waited for 25-29 weeks. The number of patients waiting between 0-9 weeks (n=95) was higher than the number of patients waiting between 10-19 weeks (n=75). This can be explained by the department aiming to see Urgent cases in 0-3 weeks, and Priority cases in 9 weeks. Hence, referrals seen in the 0-9 week period mostly reflect Urgent and Priority cases (see Figure 1).

Limitations of the Database

The "Date of first appointment" field for the Attenders related to the date of the first appointment "attended", and is the only attendance date recorded on the existing database. It is currently not possible to differentiate between date of first appointment "offered", and date of first appointment "attended". Thus, the waiting time calculations for those patients who did not attend the first appointment (i.e. the first appointment "offered"), but attended a

subsequent appointment (i.e. the first appointment "attended") were flawed, whereby the patient would appear to have waited longer for an appointment than was the case.

The waiting time calculations for some patients who never attended were also potentially flawed for the same reason. That is, if a patient was to DNA or cancel their first appointment, request another appointment date from the department, but then DNA or cancel this second appointment too, it is not clear which of the two appointment dates is currently being entered onto the database in the "Date of first appointment" field. If the date of the last appointment offered to the patient before discharge is being entered into this field, then it would appear that the patient waited longer for an appointment than was the case.

Approximately a third of Urgent (n=31, 33%), and exactly half of Priority (n=38, 50%) referrals waited longer than the department's aims of 0-3 weeks, and 9 weeks respectively. The flaws in the waiting time calculations described above could explain this for some of these referrals. However, because both the proportion of patients who DNA their first appointment but then subsequently attend, and the number of patients who "double" DNA are not currently known, it is important that these flaws are considered within this context. It is therefore not possible to state exactly how many of the Urgent and Priority cases in this study waited longer than set out in the department's aims.

Waiting Time and Attendance / Non-Attendance

The second aim of the report was to establish the impact of waiting time on the rates of attendance and non-attendance, and to determine whether waiting time was a significant factor in attendance in this psychology department. The results (see Table 1) showed that there was a similar range of waiting times for Attenders (0-51 weeks) and Non-Attenders (2-

51 weeks). However, the Attenders waited a mean of 21.2 weeks, which was approximately 6 weeks less than the Non-Attenders (mean 27.4 weeks). There was an overall Non-Attendance rate of 33.5%, which was comparable to that reported by Keen *et al.*[3] in their East of Scotland study.

As stated in the introduction, patients' failure to attend appointments results in a substantial waste of precious resources. For this psychology department, a substantial amount of clinical time is being lost through non-attendance. Figure 2 shows that, although the rate of non-attendance was approximately 20% for those seen within 0-4 weeks, it increased to nearly 40% for those waiting 25-34 weeks. Once waiting time exceeded 35 weeks, the rate of non-attendance was over 50%. This association between waiting time and attendance and non-attendance was shown to be statistically significant, supporting the hypothesis that a shorter waiting time would be associated with higher rate of attendance, and a longer waiting time would be associated with a decreased rate of attendance.

Additional Factors in Attendance / Non-Attendance

It is important to note that waiting time is not the only factor that determines attendance and non-attendance. Many other factors may have been important, but were not set out to be addressed in this study. For example factors such as Age, Gender, and Category of referral may have also been important in determining attendance. These could be examined in relation to attendance in future research. Factors such as there being a resolution of the problem by the patient themselves whilst on the waiting list, might also in some cases determine non-attendance of therapy. Hence, waiting time is not the only factor involved in a patient's decision to either attend or not attend an appointment, and the results must be considered with that in mind.

Recommendations for service provision

As outlined earlier, the Attenders simply represented patients that had attended at least one appointment during the course of therapy prior to being discharged. Presently it is not possible to isolate from this group the patients who had DNA'd or cancelled their first or subsequent appointments but who then attended at a later date. This also had the effect of skewing the waiting time calculation for those cases making it appear that they had waited longer for an appointment than they actually had. It is therefore recommended that additional date field(s) be added to the existing database (such as "Date of first appointment offered", and "Was the first appointment offered attended?"). This would also help to clarify which date should be used in data entry for the Non-Attenders. It would also be useful if the service utilised the database to provide regular feedback about length of time waiting. This would be particularly useful with respect to the Urgent and Priority referrals, to help monitor if they are waiting longer than set out in the department's aims.

Like many other psychology departments in the UK, this department has recently undertaken a measure to reduce waiting lists, by introducing a waiting list initiative in the form of an opt-in system (this was not in operation for the sample of patients in the present study). The opt-in system requires patients nearing the top of the waiting list to confirm that they still wish to have an appointment. If a patient fails to reply after two weeks of the letter being sent out, they are taken off the waiting list. It is also felt that patients who confirm that they still wish to have an appointment would be more likely to attend.

In the present study, patients who waited for 35 weeks or more were particularly vulnerable to non-attendance. In future research, any effect that introducing the opt-in system had on the pattern of attendance and non-attendance in relation to waiting time could be established. In

particular, it would be useful to establish whether, following opt-in, patients who waited for 35 weeks or more were still vulnerable to non-attendance. If this pattern continued, even with patients who had opted-in, it is recommended that the department considers how it might look at providing some additional support to patients who will be coming off the waiting list at 35 weeks, in order to try and increase the rate of attendance at that time.

Conclusions

Despite some of the limitations of the current dataset described above, this study has highlighted that waiting time is an important factor in attendance and non-attendance in this adult clinical psychology department. The hypothesis that a shorter waiting time would be associated with higher rate of attendance, and a longer waiting time would be associated with a decreased rate of attendance was supported. However, the importance of other additional factors in determining attendance was also highlighted.

It is recommended that the department monitors waiting times by utilising the database to provide feedback. This will help to identify Urgent and Priority cases that might potentially be waiting longer for an appointment than set out in the department's aims. In addition, the study has highlighted that a substantial amount of clinical time is currently being lost through non-attendance in this department, particularly with waiting times of 35 weeks or more, whereby over 50% of patients are failing to attend. Following the recent introduction of an opt-in system, non-attendance could potentially be reduced at this "vulnerable" time, and it is recommended that this be evaluated in future research. However, if this pattern continues despite patients opting-in, it is recommended that the department consider how it might look

at providing some additional support to patients coming off the waiting list at 35 weeks, in order to try and increase the rate of attendance at that time.

References

1. British Psychological Society, Division of Clinical Psychology (1993) Report of the DCP survey of waiting lists in NHS clinical psychology services: 1992. *Clinical Psychology Forum*, **53**, 39-42.
2. Conaghan, S., Traynor, E., Davidson, K., and Ralston, G. (2000). The efficacy of opt-in systems: evidence to the contrary. *Clinical Psychology Forum*, **138**, 36-38.
3. Keen, A., Blakey, R., and Peaker, A. (1996). The effects on non-attendance and early discontinuation of enclosing an information leaflet to prospective clients for clinical psychology. *Clinical Psychology Forum*, **96,** 33-35.
4. Loumidis, K.S., and Shropshire, J.M. (1997). Effects of waiting time on appointment attendance with clinical psychologists and length of treatment. *Irish Journal of Psychological Medicine,* **14(2),** 49-54.
5. Morton, A. (1995). The enigma of non-attendance: A study of clients who don't turn up for their first appointment. *Therapeutic Communities International Journal of Therapeutic and Supportive Organisations,* **16(2)**, 117-133.
6. Weighill, V.E., Hodge, J., Peck, D.F. (1983). Keeping appointments with clinical psychologists. *British Journal of Clinical Psychology*, **22**, 143-144.
7. Lloyd, M., Bradford, C., and Webb, S. (1993). Non-attendance at Outpatient Clinics. Is it related to the referral process? *Family Practice*, **10(2)**, 111-117.
8. Howell, D.C. (1997). *Statistical Methods for Psychology, 4th Ed.* London: International Thomson Publishing.

LIST OF TABLES AND FIGURES

List of Tables:

		Pages
Table 1.	Waiting Times for Attenders and Non-Attenders.	**17**
Table 2.	Breakdown of the numbers of Attenders, Non-Attenders, and Total numbers.	**18**

List of Figures:

		Pages
Figure 1.	Waiting Times for Attenders and Non-Attenders.	**19**
Figure 2.	Relative percentages of attendance and non-attendance by patients (categorised according to block of waiting time).	**20**

Table 1. Waiting Times for Attenders and Non-Attenders

	Waiting Time (weeks)			
	Mean	SD	Min.	Max.
Attenders (n=341)	21.2	11.8	0	51
Non-Attenders (n=172)	27.4	12.0	2	51

Table 2. Breakdown of the numbers of Attenders, Non-Attenders, and Total numbers for each block of waiting time.

Waiting time (weeks)	0-4	5-9	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54
Number of Attenders	32	42	28	32	73	54	39	17	14	6	4
Number of Non-Attenders	7	14	6	9	31	33	21	22	17	7	5
Totals	39	56	34	41	104	87	60	39	31	13	9

Figure 1. Distribution of waiting times according to referral category

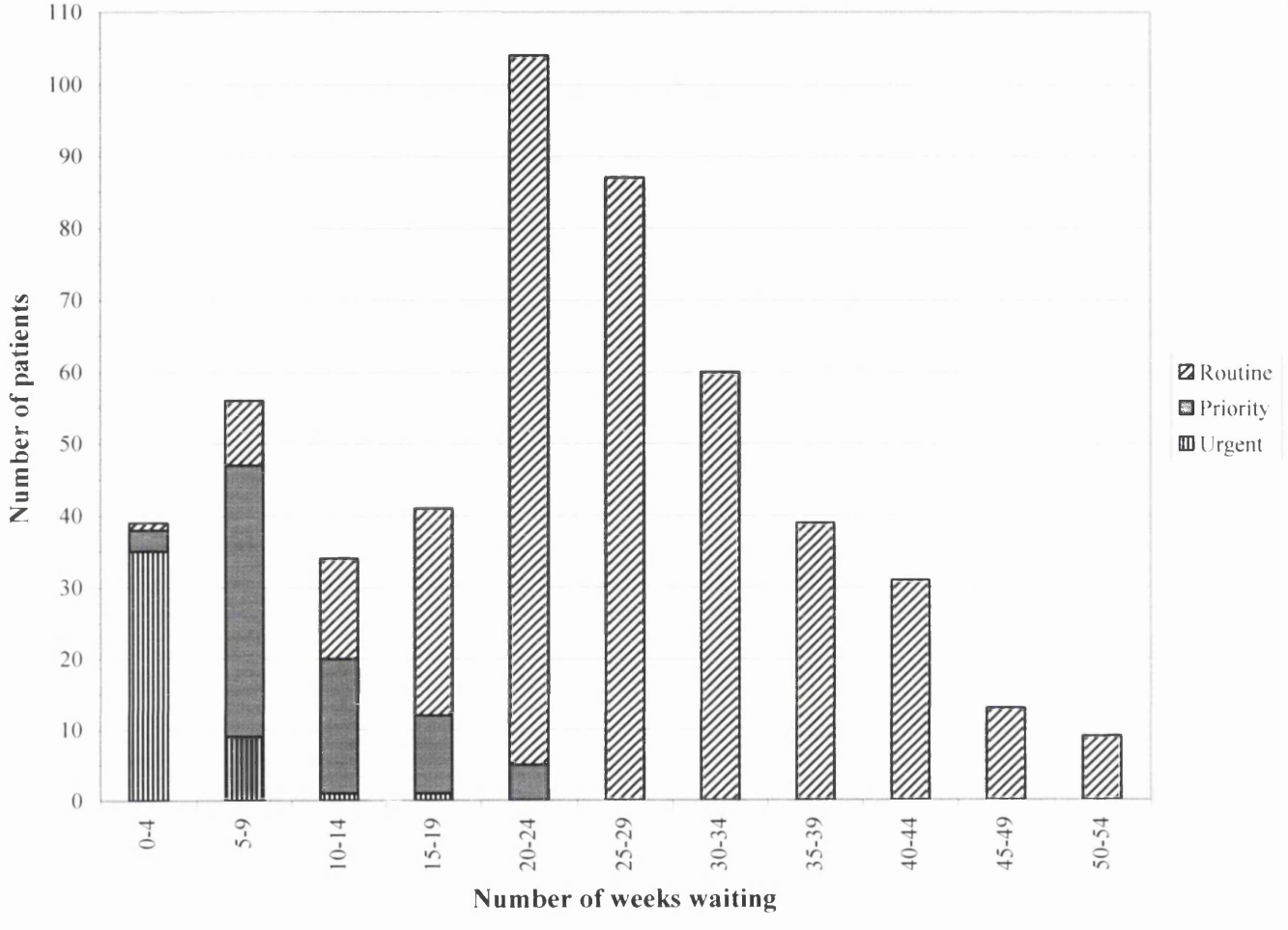
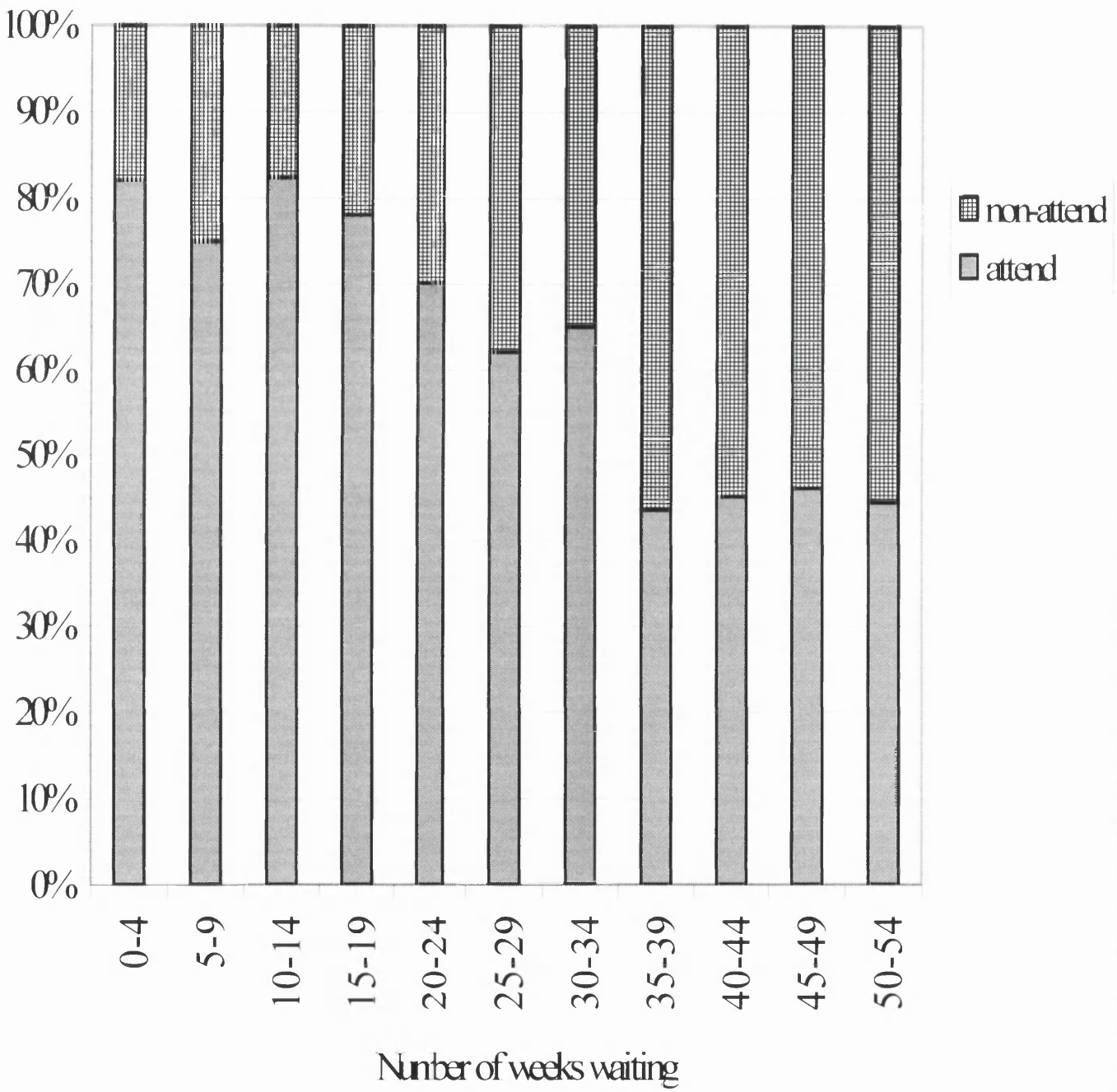


Figure 2. Relative percentages of attendance and non-attendance by patients (categorised according to block of waiting time).



3. MAJOR RESEARCH PROJECT PROPOSAL

The Importance of Facial Appearance in Patients with Eye Cancer

Prepared in accordance with the D. Clin. Psy. Handbook guidelines and those issued by the West Ethics Committee.

The Importance of Facial Appearance in Patients with Eye Cancer

Applicant:

Nicola J. Brown
Trainee Clinical Psychologist
Dept. of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Supervisor:

Dr Craig A. White
Cancer Research UK Fellow in Psychosocial Oncology
Dept. of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Summary

Eye cancer patients have to not only cope with a life threatening diagnosis, but also with a potentially altered facial appearance as a result of treatment. Hence, their self-concept in relation to the appearance of their face may be threatened resulting in body image disturbances. This systematic review aims to establish the scope and quality of the existing body image / appearance research in an eye cancer population.

Only two studies met the inclusion criteria for the review and these authors did not base their investigations on any definition or model of body image. In addition, there were no dedicated, validated, questionnaires used that asked specifically about appearance. Due to the low number of studies identified, the review was expanded to include head and neck cancer patients. Here thirteen studies met the inclusion criteria. However, overall the research that had examined body image or appearance factors in head and neck cancer was also of generally poor quality.

It is difficult to draw definite conclusions owing to the paucity of the literature. Further work examining body image dimensions as the main focus of investigation in facial cancer is therefore needed, in order that this area is not further neglected.

1. Introduction

There is evidence to suggest that there is a high prevalence of psychological disorder in cancer patients. For example, Derogatis *et al.* (1983) found that, using DSM-III criteria (American Psychiatric Association, 1980), 47% of cancer patients received a diagnosis. Of these patients, 85% were experiencing a disorder with depression or anxiety as the central symptom. Zabora *et al.* (2001) reported an overall prevalence rate of distress of 20%. They concluded that there is a great need to identify high-risk patients through psychosocial screening in order to provide early intervention. Thus, given the distress experienced by many cancer patients, the importance of clinicians' understanding of psychosocial adjustment to cancer has been emphasised (Brennan, 2001).

Eye and adnexa[1] cancer is a rare form of cancer and is the only ocular disease that directly threatens life (Kleinstein and Lehman, 1977). It is associated with a five-year mortality rate of 35% and a ten-year mortality rate of nearly 50% (Cruickshanks *et al.*, 1999; Brandberg *et al.*, 2000), with metastasis occurring mainly to the liver. There are only approximately 40 new cases recorded each year in Scotland, with a male: female ratio of approximately 1:1 (Harris *et al.*, 1998). The most common primary intraocular (within the eye) malignancy is posterior uveal melanoma (melanomas derived from the pigmented uveal tract of the eye). This incorporates the iris, ciliary body and the choroid (the vascular coat of the eye between the sclera and the retina) (see Figure 1).

INSERT FIGURE 1 ABOUT HERE

[1] For the purposes of this research, "eye cancer" will be used to refer to "eye and adnexa cancer", whereby adnexa are the adjoining anatomical parts of the eye.

Factors that influence treatment choice in eye cancer patients include size, extent and location of the tumour. Patients who have medium or large sized tumours that are growing, can be managed with either radiotherapy or local resection of the tumour. Patients who have large tumours that have produced severe visual loss, are more likely to be managed by enucleation (removal of the eye) (Sisley, 1999). No differences in survival have been reported for patients treated by these methods of treatment. (Seddon *et al.*, 1985).

Eye cancer patients like all cancer patients are therefore at risk of developing psychological disorders. In addition to having to cope with a life threatening diagnosis, they also have to cope with a potentially altered facial appearance as a result of treatment. Therefore, self-concept may also be threatened resulting in disturbances in body image.

Higgins' (1987) Self-Discrepancy Theory suggests that the "self" has multiple aspects that develop through both internal self-evaluations and interpersonal experiences. These aspects are also dynamic as, in response to external events (such as a cancer diagnosis), they may be changed or modified. In this theory, two of the components are the *ideal* / self and the *actual* / self. Ideal / self refers to the aspirations as to who one could potentially be, whereas actual / self refers to conceptions as to who one really is. Higgins (1987) proposed that individuals are motivated to achieve a match between their ideal / self and actual / self because a discrepancy would result in psychological distress (experienced as either depression or anxiety). A diagnosis of cancer is particularly threatening to the ideal / self because it is associated with both fear of pain and death due to the disease, and fears of painful and debilitating and

possibly disfiguring treatment. Receiving a diagnosis of cancer is therefore a particularly potent motivation for engaging in adjustments related to the self (Curbow *et al.*, 1990).

The Social Sciences Citation Index (SSCI) holds citation data from 1981 to 2002 and is updated monthly. Using this database, over 550 articles to date had cited Higgins (1987). The majority of the citations that had examined body image dimensions were within the eating disorders field and had focused on weight-related appearance. Only one study that had cited self-discrepancy theory had been carried out with cancer patients (Heidrich *et al.,* 1994). They investigated whether or not self-discrepancies were related to psychological well-being and distress in twenty life domains by asking patients to rate ideal / self and actual / self in each domain. Items included "my physical health", "coping with change" and "pursuing my leisure interests and hobbies". The authors did not examine body image or appearance related issues in detail in these cancer patients as there was only one item relating to ideal / self and actual / self in the domain of "physical appearance".

Cash and Szymanski (1995) highlighted that previous body image research has tended to regard all physical attributes as if they were of equal importance. They proposed that it is the degree to which someone places *importance* on a perceived ideal / self actual self discrepancy that is important, and not merely the discrepancy being present. Thus, an ideal / actual self-discrepancy of major importance (i.e. one that has high *investment*) will have a significant psychological impact, being equivalent to having multiple ideal / actual self-discrepancies that are each associated with lesser degrees of importance. By combining the concept of investment with Higgins' (1987)

self-discrepancy theory, they were able to account for the differential degrees of importance that are placed on physical features by different people.

Again using the Social Sciences Citation Index (SSCI), 17 studies to date had cited Cash and Szymanski (1995). Here the concept of investment had been applied mainly to the eating disorders field in studies using college females and had not been used at all in cancer research.

Although the concepts of self-discrepancy theory and investment have not been widely applied to the cancer field in terms of body image research, it is not known what, if any, other body image research exists in patients with eye cancer. Thus a systematic review of studies that have examined the impact of facial appearance change in eye cancer patients is needed.

2. Systematic Review

2.1 Eye Cancer

This review aims to establish the scope and quality of the existing body image / appearance research in an eye cancer population.

Criteria for studies to be considered:

Study Designs

Randomised trials, cohort studies, case control studies and cross-sectional studies.

Participants

Patients aged 18 or over, where eye cancer is the primary diagnosis, with the onset of this occurring in adulthood.

Types of Studies

Criteria for selection included literature that had addressed any or all of the following as main outcome measure(s):

1. Body Image.
2. Appearance.
3. Disfigurement.

Search strategies for identification of studies:

Databases: Medline, PsycINFO, Embase, Cinahl, Cochrane Collaboration.

Years: 1967-2002 (up to and including June).

Search Terms:

1. All references to "body image", or "appearance", or "disfigurement" combined with: **AND** "eye cancer", or "ocular cancer", or "choroidal melanoma", or "posterior uveal melanoma".
2. All reference lists electronically identified were subsequently hand searched.

Methods of review

Selection of studies: All potential studies were reviewed by the author to determine if they fulfilled the inclusion criteria.

Data Abstraction: Data were abstracted from each article relating to study design and quality, patient demographics, measurement instruments and outcomes.

Quality Assessment:

Studies were graded according to their design (Table 1). These gradings were based on quality gradings assigned by MacMahon and Lip (2002).

INSERT TABLE 1 ABOUT HERE

Summary of studies identified:

Eleven studies were identified that had reported on the issues listed above.

Excluded studies.

Nine studies in total were excluded:

Five studies were excluded on the basis that they did not meet study design criteria for inclusion:

- Two studies (Trunc *et al.*, 1997; Damato, 2000) were editorials.
- One paper (Kennedy, 2000) was the narrative experience of an eye cancer sufferer.
- One paper (Moy and Melia, 1999) was a descriptive outline of the design and methods of a future study: The Collaborative Ocular Melanoma Study.
- One study (Foss *et al.*, 2000) described the development and validation of a patient based measure of outcome in ocular melanoma.

Three studies were excluded on the basis that they did not meet participant criteria for inclusion:

- One study (Hart *et al.,* 1998) had been carried out with ophthalmologists and not patients.
- In one study (Linberg *et al.,* 1988), only eighteen out of the sample of one hundred and twenty five patients had had enucleations as a result of intraocular tumour. The majority of the enucleations (84 out of 125) had been performed as a result of ocular trauma.
- In another study (Rubin *et al.,* 1998), only four out of the sample of thirty-nine patients had had enucleations as a result of intraocular tumour. The majority of the enucleations (31 out of 39) had been performed as a result of ocular trauma.

One study was excluded on the basis that it failed to meet both participant criteria and study design criteria for inclusion:

- Webb (1990) had described the establishment of a support group for parents of children with eye cancer.

Included studies

There were only two studies (Brandberg *et al.,* 2000; Bunston *et al.,* 1994) that met the inclusion criteria for this review.

Design

Both studies (Brandberg *et al.,* 2000; Bunston *et al.,* 1994) had investigated appearance factors using a cross-sectional design.

Setting

One study was carried out in Canada (Bunston *et al.*, 1994) and the other in Sweden (Brandberg *et al.*, 2000). See Table 2 for a summary of these studies.

INSERT TABLE 2 ABOUT HERE

Discussion of the two included studies

The study by Bunston *et al.* (1994) was carried out in two phases. The first phase was the development and verification of the reliability and validity of an inventory to identify the non-medical concerns of ocular melanoma patients, which would be used in the second phase. This resulted in an inventory of 58 non-medical concerns of the patients organised into fourteen need/concern domains, one of which was 'self image'. They stated that their validation process had involved examining content, concurrent, convergent/divergent validity and test re-test reliability. However, they did not report any validity figures for these procedures. It was therefore unclear what the validity and reliability of the instrument actually was.

In the second phase, a cross-sectional study of 96 patients with ocular melanoma was carried out using the measure derived in the first phase. A criticism of this approach was that the patients were not divided into groups, which meant there were no comparisons made. Concerns were simply identified as being present in each domain if each patient had identified one or more need. Thirty-eight patients (39.6%) expressed concern regarding self image. However, the authors did not specify how many needs were in each domain, nor did they report any of the items. It was

therefore difficult to ascertain to what extent there was concern in relation to self image.

Overall the layout of this paper was poor, which had an adverse effect on its clarity. The authors appear to have attempted to fit too much into one paper, with the result of the overall quality being compromised.

Brandberg *et al.* (2000) examined psychological reactions in 99 patients with posterior uveal melanoma. The Eye Symptom Questionnaire, (Brandberg *et al.*, 2000) was administered one year following treatment. This is a non-validated 15-item questionnaire, which was developed for the study. It is now also being developed further for the 'ophthalmic module' of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30, Aaronson *et al.*, 1993). The Eye Symptom Questionnaire included two items asking about appearance. These were rated by the patient on a four point Likert type scale in relation to the previous week. Ratings were: 'not at all', 'a little', 'quite a bit', or 'very much'. The two items were:

1) Has your appearance bothered you?
2) Were you dissatisfied with the cosmetic result of the surgery?

The authors compared those treated with ruthenium plaque therapy (n=32) to those treated with enucleation (n=46). They found that a higher percentage of those who were treated with enucleation had problems with appearance (54.6%) compared to those treated with ruthenium plaque therapy (13.2%) based on these two questions.

The eye symptom questionnaire has not yet been adequately validated and therefore the results have to be interpreted within these constraints.

Conclusions

This systematic review has established that the existing literature examining body image and appearance in an eye cancer population is extremely sparse. In addition it has shown that what does exist is limited both in scope and quality. Only two research papers had investigated appearance issues in an eye cancer population, and their investigations were not based on any definition, theory or model of body image. In addition there were no dedicated, validated, questionnaires used that asked specifically about appearance. Instead their enquiries only extended to one or two questions relating to appearance out of a whole battery of measures. Perhaps this lack of research reflects the fact that eye cancer is a rare form of cancer.

Due to the low number of studies identified, it was not possible to draw any definite conclusions about the experience of facial appearance change as a result of eye cancer. Hence, the review was widened to also include head and neck cancer patients.

2.2 Head and Neck Cancer

Cancer of the head and neck is more common than eye cancer and accounts for approximately 5% of all malignant tumours (Million *et al.*, 1989). As a result it is likely to have attracted more research interest than eye cancer. Strictly speaking, the term 'head and neck' cancer incorporates all cancers that develop in the oral cavity and sinuses, the ears, nose, lips, mandible (principal bone in the lower jaw), larynx,

pharynx, and oesophagus (Petrucci and Harwick, 1984). However, sometimes oral cancers are described separately to head and neck cancer.

Head and neck cancer surgery may involve a laryngectomy (surgical removal of all or part of the larynx), the partial or total removal of a tongue or mandible, or the loss of an ear among other disfigurations. Speech is often affected and, postoperatively, patients are often confronted with a permanent tracheal opening, a limited range of motion in the upper extremity, modifications in eating and grooming and obvious changes in appearance.

There are obvious similarities between eye cancer and head and neck cancer. They each affect vital functions, i.e. sight (eye cancer), swallowing and speech (head and neck cancer). In addition, visible facial disfigurement may result from either the treatment and/or the disease in both conditions. On this basis, it was deemed to be appropriate to expand the terms of this review to incorporate head and neck cancer (including oral cancer) literature that had examined appearance as a primary outcome in facial disfigurement in order to help inform the current status of body image research in facial cancers.

Criteria for studies to be considered:

Study Designs

Randomised trials, cohort studies, case control studies and cross-sectional studies.

Participants

Patients aged 18 or over, with head and neck / oral cancer as the primary diagnosis, with the onset of this occurring in adulthood.

Types of Studies

Criteria for selection included literature that had addressed the following issues:

1. Body Image.
2. Appearance.
3. Disfigurement.

Search strategies for identification of studies:

Databases: Medline, PsycINFO, Embase, Cinahl, Cochrane Collaboration

Years: 1967-2002 (up to and including June).

Search Strategies:

1. All references to "body image", or "appearance", or "disfigurement" combined with: **AND** "head and neck cancer", or "oral cancer" or "facial cancer".
2. All reference lists electronically identified were subsequently hand searched.

Methods of review

Selection of studies: All potential studies were reviewed by the author to determine if they fulfilled the inclusion criteria.

Data Abstraction: Data were abstracted from each article relating to study design and quality, patient demographics, measurement instruments and outcomes.

Quality Assessment: Studies were graded according to their design (Table 1).

Summary of studies identified

Twenty seven studies were identified that had investigated body image, appearance or disfigurement as a main outcome variable in head and neck cancer patients.

Excluded studies.

Fourteen studies in total were excluded:

Thirteen studies were excluded on the basis that they did not meet study design criteria for inclusion:

- Three studies (Morris, 1994; Owen *et al.,* 2001; Rogers, 2001) were editorials.
- Ten studies (Anand and Anand, 1997; Bronheim *et al.,* 1991; David and Barritt, 1982; Droughton, 1990; Koster and Bergsma, 1990; McQuellon and Hurt, 1997; Shapiro and Kornfeld, 1987; Strauss, 1989; Turns and Sands, 1978; van Doorne *et al.,* 1994) were descriptive.

One study was excluded on the basis that it did not meet participant criteria for inclusion:

- Lockhart (1999) was a study of nurses' perceptions of severity of facial disfigurement in head and neck cancer patients following surgery.

Included studies

There were 13 studies (Baker, 1992; Devine *et al.,* 2001; Dhillon *et al.,* 1982; Dropkin, 1979; Dropkin, 1999; Dropkin, 2001; Freedlander *et al.,* 1989; Gamba *et al.,* 1992; Krouse *et al.,* 1989; Kwok *et al.,* 2002; Monga *et al.*, 1997; Morton *et al.,* 1984; West, 1977) that met the inclusion criteria for this review.

Design

Twelve studies (Baker, 1992; Devine *et al.,* 2001; Dhillon *et al.,* 1982; Dropkin, 1979; Dropkin, 1999; Dropkin, 2001; Freedlander *et al.,* 1989; Gamba *et al.,* 1992; Kwok *et al.,* 2002; Monga *et al.*, 1997; Morton *et al.,* 1984; West, 1977) were cross-sectional designs. One study (Krouse *et al.,* 1989) was prospective longitudinal in design.

Setting:

One study was carried out in Scotland (Freedlander *et al.,* 1989), one study (Kwok *et al.,* 2002) in New Zealand, seven in the United States (Baker, 1992; Dropkin, 1979; Dropkin, 1999; Dropkin 2001; Krouse *et al.,* 1989; Monga *et al.*, 1997; West 1977), one in Italy (Gamba *et al.,* 1992), and three in England, (Devine *et al.,* 2001; Morton *et al.,* 1984; Dhillon *et al.,* 1982). See Tables 3a and 3b for a summary of these studies.

INSERT TABLE 3A AND 3B ABOUT HERE

There were two types of study identified:

a) Studies investigating the impact of disfigurement from head and neck cancer on another outcome variable.

The variables investigated were:

- Social adjustment patterns (West, 1977).
- Social interaction (Dropkin, 1979).
- Rehabilitation (i.e. eating, recreation, sleep, home life, work) (Baker, 1992).
- Self image (Gamba *et al.*, 1992).
- Coping and length of stay in hospital (Dropkin, 1999).
- Post-operative levels of anxiety (Dropkin, 2001).
- Sexual functioning (Monga *et al.*, 1997).

b) Studies assessing the effect of having head and neck cancer on body image or appearance as a main outcome variable.

i) Cross-sectional

These studies all assessed the effects of different treatments for head and neck cancer on body image or appearance (Devine *et al.*, 2001; Dhillon *et al.*, 1982; Freedlander *et al.*, 1989; Kwok *et al.*, 2002; Morton *et al.*, 1984).

ii) Prospective longitudinal

This study assessed body image as a main outcome variable (Krouse *et al.*, 1989) without comparing groups.

Critical discussion of the included head and neck cancer studies in chronological order

The studies are reviewed in chronological order to establish if the era of publication had any bearing on the quality of the study produced.

An early study (West, 1977) investigated social adjustment patterns of facially disfigured head and neck cancer patients. The inclusion criterion was 'a visible disfigurement'. However, there was no definition of what constituted a visible disfigurement and it was assigned without the guidance of a scale. Social adaptation was ascertained by asking patients how well they had adapted to being disfigured in fourteen areas (including socialising with work colleagues and going out in public) using a non-standardised measurement tool. It was concluded simply that 86.2% of people had adapted "very well" to being disfigured. It was unclear how this conclusion was reached.

Dropkin (1979) was a particularly poor quality of paper achieving the lowest quality grading possible. The sample size was small (n=10) and they were all male. Degree of a patient's deformity was assigned a number but there was no further reference to either how this number was assigned, or what it meant. Degree of deformity was compared to time spent out of hospital bedroom and this was recorded by nursing staff. Dropkin (1979) reported that the more disfigured the patient was post-operatively, the less time he spent voluntarily out of his room. She concluded that this suggested that social interaction decreased as deformity increased. However, there could have been any number of reasons why the patient decided not to come out of his

room. For example, higher deformity may have been associated with more pain, but the patients were not asked to contribute their opinions to the study.

Unlike either of the studies reviewed so far, Dhillon *et al.* (1982) set out to establish the patient's view of the extent of their disfigurement following laryngectomy (n=35), or commando (excision of a primary tumour in the oral cavity combined with radical neck dissection and flap repair) (n=14) procedures. The 'cosmetic' assessment was achieved by means of a questionnaire that the patients were asked to return to the investigator by mail. The contents of this questionnaire were not described in the paper, therefore it is impossible to ascertain what the patients were asked.

It was reported that four patients (28%) considered themselves 'severely' disfigured and four (28%) 'moderately' disfigured by the commando operation. In contrast, the laryngectomy procedure had changed the facial appearance of only one patient (2.8%). The authors did not report any further results from the questionnaire. Hence, it is impossible to know how the remaining patients felt about their appearance. For example, it would have been useful to know whether or not any of the laryngectomy patients felt 'moderately' disfigured and how many patients felt mildly or not disfigured. In addition, the number of patients in the commando group was fairly low so the result must interpreted within the constraints of this.

Morton *et al.* (1984) set out to assess the effects of treatment type on quantitative measures of quality of life where appearance was one of the main outcomes. Overall they had a reasonable number of patients (n=48), although they were all male. In order to provide three groups for the purpose of comparisons they divided the patients

up into Radiotherapy alone (n=19), Salvage surgery after failed radiotherapy (n=17) and Surgery alone (n=12). This meant the numbers in each group were fairly low.

The appearance measure used was the Body Satisfaction Scale. This was a non-standardised in-house measure that was constructed for the purpose of their research. Patients were asked to rate satisfaction with the appearance of named parts of the body using a four-point scale. However, the authors did not give any details about the types of body parts that had been included. They also did not provide any scoring information, except to state that a high score indicated 'dissatisfaction' with several body parts and that the maximum score was 'seven'. They also stated that only 'explicit dissatisfaction' with a body part was scored, without any definition of what constituted explicit dissatisfaction or further explanation as to how this was decided.

They concluded that overall 53% felt that their looks had been affected and that the salvage surgery after failed radiotherapy group had the highest body dissatisfaction, followed by the surgery alone group. They did not state what statistical procedures had been used and did not consider the power of these calculations given the low number of patients in each group. It was difficult to interpret how they had arrived at these conclusions with such little information about the scale reported.

In a brief paper, Freedlander *et al.* (1989) asked 41 patients about their concern for appearance following major surgery for intraoral malignancy. Following neck dissection, patients who had had reconstructive surgery were compared according to the type of procedure they had. Reconstruction was achieved by either a free radical forearm flap procedure (n=27), or a distant pedicled flap procedure (e.g. involving the

forehead) (n=14). The authors did not provide any further descriptive detail about the differences between these two procedures. They used an in-house measure to establish any embarrassment the patients had experienced in relation to their appearance, the details of which were not reported. They reported that there was no significant difference between the groups and that overall 20-25% had moderate to severe embarrassment in relation to their appearance. In addition, 15% of men compared to 43% of women were concerned about their appearance. The limitations of this study were that the patient numbers in groups were quite low and the measure used was not validated.

Krouse *et al.* (1989) carried out a prospective longitudinal assessment of adults who had undergone surgery for head and neck cancer pre-operatively, at 3 months and 9-12 months post-operatively to assess body image as a main outcome variable. They used a non-standardised measure, the Body Image Questionnaire (Berscheid *et al.* 1972). The sample size was quite small (n=33) and they did not make any group comparisons. They reported that 95% of the patients rated their appearance as 'average' to 'excellent' pre-operatively and that this percentage remained constant post-operatively over a one year period. Thus they concluded that body image and appearance did not contribute significantly to post-operative adjustment. Although they had three time points for data from the Body Image Questionnaire, as this is a non-standardised tool, these conclusions must be considered within these constraints.

Baker (1992) set out to determine the relationship of facial disfigurement to rehabilitation outcomes. Some progress in establishing the presence of disfigurement was made in this study compared to the two earlier studies, in that a scale was used.

Extent of facial disfigurement was recorded using the Disfigurement-Dysfunction (D/D) scale (Dropkin *et al.* 1983).

The D/D scale was developed based on the ratings of registered nurses of photographs of patients with simulated defects intended to represent eleven specific surgical procedures. Each procedure was rated as 'no disfigurement', 'minor', 'moderate' or 'severe'. However, by using the type of surgical procedure as the means of determining the degree of disfigurement, this scale does not take into account individual differences in the cosmetic result attributable to differences in reconstructive technique, previous radiation, or occurrence of post-operative complications. In addition, the reported reliability and validity is limited to consensus by "a panel of experts" but they did not state what this consensus involved.

Baker (1992) reported that a high degree of facial disfigurement was associated with problems with eating and recreation, but it was not associated with sleep, home management or work. On this basis, they concluded that facial disfigurement was not an impediment to successful rehabilitation in head and neck cancer. As the design was correlational, it is not methodologically sound to draw this conclusion. Another major criticism is that the subjective experience of patients was not included, as they were not asked about their body image, with degree of disfigurement being assigned only by the investigator.

Gamba *et al.* (1992) set out to establish extent to which disfigurement affected self-image, relationship with partner, family and friends and overall impact of therapy. They compared those with minor disfigurement (n=24) to those with extensive

disfigurement (n=42). Although this study is an improvement on earlier studies because it has used group comparisons, a criticism is that the assignment of disfigurement as either minor or major was not achieved by using a scale. Instead a Physician's opinion and not patient's perception was used to allocate the patients to either the minor or extensive disfigurement groups, compromising the reliability of group allocation.

Gamba *et al.* (1992) reported that more of the extensively disfigured patients had a changed self image (57%) compared to the minor disfigured group (25%). However, this was ascertained by a non-standardised measurement tool assessing self image without any theoretical basis. In addition, although they reported changed self image, they do not extend this enquiry to find out *how* self image had changed. Therefore, this study is limited in terms of what it contributes to body image research.

Monga *et al.* (1997) examined the relationship between sexual functioning and disfigurement in patients with head and neck cancer using the clinician administered D/D scale (Dropkin *et al.*, 1983) and the Derogatis Inventory of Sexual Functioning (Derogatis, 1996). Using the D/D scale, 28 patients had no disfigurement, 9 had minor disfigurement and 18 had extensive disfigurement. They reported that the extent of disfigurement was not significantly correlated with sexual functioning, although there was a trend towards poorer sexual functioning in patients with extensive disfigurement. They also reported that patients with extensive disfigurement felt more unattractive and older. They did not describe the statistical procedures that had been applied to their data and did not report any significance values, so it is difficult to ascertain how reliable the outcome of this study is.

Dropkin (1999) stated that the purpose of this study was to describe coping ability and the degree of post-operative disfigurement in relation to length of hospital stay. However, she assessed 117 adults and reported that coping ability decreased with *anticipation* of disfigurative surgery. It was not clear what procedure she had followed to come to this conclusion. In addition, although she assessed the degree of post-operative disfigurement using the D/D scale, she did not report this in relation to length of hospital stay as had been outlined in her aim. This paper would have received the lowest quality grading possible had it not been for the fact that there were a large number of patients in the cohort.

In a similarly designed study to that reported two years earlier, Dropkin (2001) assessed 75 patients following disfigurative surgery for head and neck cancer to determine levels of anxiety. She concluded that, although mean anxiety scores decreased over time, there was no significant correlation between disfigurement (measured using the D/D scale) and post-operative anxiety. She did not state how she had determined this, simply stating that data had been "analysed" and reported no significance figures. There were a reasonable number of patients in the cohort.

Devine *et al.* (2001) set out to compare the effects of two surgical procedures for previously untreated oral carcinoma on facial appearance. The first surgical technique was lip split mandibulotomy (n=10), which involves incision of the lower lip in continuity with the neck dissection incision. The second technique was mandible release (n=10). The authors did not hypothesise which technique they believed would result in a preferable aesthetic outcome. Following the surgical procedure, an overall aesthetic assessment of the patient's face and neck was made by the clinician and

scored using a seven point linear analogue scale, whereby '1' was 'highly satisfactory' and '7' was 'highly unsatisfactory'. Lay observers also scored the overall appearance of the patients using photographs and at the end of the clinical examination, the patients were asked to score their own face and neck appearance using the same scoring system. The authors also administered the disfigurement questions from the University of Washington Quality of Life assessment (UW-QOL) (Hassan and Weymuller, 1993).

The authors reported using ANOVA for their comparisons between the groups. This is considered hazardous due to the sample sizes being so small and results must be interpreted as inconclusive for this reason. They reported that, although the clinician tended to rate patients as having a more satisfactory appearance than laypersons or patients, there were no significant differences between the groups on any of the aesthetic ratings or on the UW-QOL disfigurement questions. Their conclusion was that there was no difference in aesthetic outcome between these two procedures.

Kwok *et al.* (2002) investigated appearance related quality of life in patients treated for parotid gland (n=13) or temporal bone (n=10) cancer. The parotid gland is situated near to the ear, while the temporal bone is the thick bone that encases the inner ear. Thus, they compared those who had had temporal bone resection (TBR) to those who had had parotidectomy plus radiation (P+RT). Disfigurement was rated on the basis of presence or absence of the outer projecting portion of the ear (pinna) and the reconstruction flap. In addition patients were asked to rate the impact of their appearance changes using two questions, one from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (Head and Neck

specific module) (EORTC QLQ–H&N35) (Bjordal *et al.*, 1994) and one from the University of Washington Quality of Life assessment (UW-QOL) (Hassan and Weymuller, 1993).

They used a Mann Whitney test to show that the TBR group had significantly poorer cosmetic outcome and lower appearance related quality of life but only on the UW-QOL item. There was only a moderate correlation between the UW-QOL appearance item and the EORTC QLQ-H&N35 appearance item.

There are several problems with this study. Firstly, the authors based patients' appearance related quality of life on only two questions from different questionnaires. They also used a non-standardised, dichotomous (presence or absence) type of rating of disfigurement. In addition, the numbers in each group were very small so caution must be taken when accepting these results due to low power.

Conclusions

The era of publication did not appear to influence the quality of the research, with fairly poor quality research being carried out as recently as 2001. The major criticisms identified in this systematic review of head and neck cancer of the body image / appearance research can be summarised as follows:

1. None of the studies identified based their enquiries on a clear definition or psychological model of body image or appearance change following head and neck cancer.

2. Researchers tended to use non-standardised or problematic measures of observer rated disfigurement. They also used either one or two items from a general quality of life questionnaire to assess appearance related quality of life, or a non-standardised measure of appearance related quality of life.

3. Quite often studies without groups were employed. In addition, in those studies that had used groups, although the groups were often well matched, there were often low numbers in each group. In these cases statistical procedures were often carried out when the number of patients in each group should have precluded this.

In an attempt to overcome some of the problems with observer ratings of disfigurement, Katz *et al.* (2000) developed the observer rated disfigurement scale for head and neck cancer. This is a simple nine-point scale with numbers from 1 to 9 corresponding to extent of disfigurement. It also provides examples of what constitutes minimal, moderate and severe disfigurement on the scale (see Appendix 2.2). If this scale is used for the objective measurement of disfigurement combined with improvements in the other areas discussed, then the quality of research in this field should improve dramatically.

Overall the research that has examined body image or appearance factors is sparse with respect to eye cancer and of poor quality in head and neck cancer. It is therefore difficult to draw definite conclusions owing to the paucity of the literature. Further work examining body image dimensions as the main focus of investigation in facial cancer is therefore needed, in order that this area is not further neglected. White

(2000) has applied Higgins' (1987) self-discrepancy theory and Cash and Szymanski's (1995) work on body image to the cancer field. Here he has proposed a heuristic cognitive behavioural model of body image and cancer. However, this model has not yet been empirically tested and therefore research is needed to evaluate it.

References

Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JCJM, Kaasa S, Klee M, Osoba D, Razavi D, Rofe PB, Schraub S, Sneeuw K, Sullivan M, Takeda F. 1993. The European Organisation for Research and Treatment of Cancer QLQ-C30: A Quality of Life Instrument for Use in International Clinical Trials in Oncology. *J Natl. Cancer Inst.* **85**(5): 365-376.

American Psychiatric Association. 1980. *Diagnostic and Statistical Manual of Mental Disorders (3rd Edition)*. Washington, DC: American Psychiatric Association.

Anand SA, Anand VK. 1997. Art Therapy with Laryngectomy Patients. *Art Therapy*, **14**(2): 109-117.

Baker CA. 1992. Factors associated with rehabilitation in head and neck cancer. *Cancer Nursing*, **15**(6): 395-400.

Berscheid E, Walster E, Bohrnstedt G. 1972. Body Image: A Psychology Today Questionnaire, *Psychology Today*, **6**(2): 58-64.

Bjordal K, Ahlner-Elmqvist M, Tollesson E, Jensen AB, Razavi D, Maher EJ, Kaasa S. 1994. Development of a European Organisation for Research and Treatment of Cancer (EORTC) questionnaire module to be used in quality of life assessments in head and neck cancer patients: EORTC Quality of Life Study Group. *Acta Oncologica*, **33**: 879-885.

Brandberg Y, Kock E, Oskar K, Trampe EA, Seregard S. 2000. Psychological reactions and quality of life in patients with posterior uveal melanoma treated with ruthenium plaque therapy or enucleation: a one year follow-up study. *Eye,* **14:** 839-846.

Brennan J. 2001. Adjustment to cancer – coping or personal transition? *Psycho-Oncology* **10**: 1-18.

Bronheim H, Strain JJ, Biller HF. 1991. Psychiatric Aspects of Head and Neck Surgery Part II: Body Image and Psychiatric Intervention, *Gen. Hosp. Psychiatry*, **13:** 225-232.

Bunston T, Mackie A, Jones D, Mings D. 1994. Identifying the Non medical concerns of patients with ocular melanoma. *Journal of Ophthalmic Nursing* and *Technology* **13**(5): 227-237.

Cash TF, Szymanski ML. 1995. The development and validation of the Body Image Ideals Questionnaire. *Journal of Personality Assessment* **64**(3): 466-477.

Cruickshanks KJ, Fryback DG, Nondahl DM, Robinson NAB, Keesey U, Dalton DS, Robertson DM, Chandra SR, Mieler WF, Zakov ZN, Custer PL, Del Priore LV, Albert DM. 1999. Treatment choice and quality of life in patients with choroidal melanoma. *Archives of Ophthalmology,* **117:** 461-467.

Curbow B, Somerfield M, Legro M, Sonnega J. 1990. Self-concept and cancer in adults: Theoretical and methodological issues. *Social Science and Medicine* **31**: 115-28.

Damato B. 2000. Disease and 'dis-ease' in patients with uveal melanoma (editorial). *British Journal of Ophthalmology,* **84:** 343-345.

David DJ, Barritt JA. 1982. Psychosocial implications of surgery for head and neck cancer. *Clinics in Plastic Surgery*, **9**(3): 327-336.

Derogatis LR. 1996. *The DISF/DISF-SR Manual.* Baltimore (MD): Clinical Psychometric Research.

Derogatis LR, Morrow GR, Fetting JH, Penman D, Piasetsky S, Schmale AM, Henrichs M, Carnicke CLM. 1983. The prevalence of psychiatric disorders among cancer patients. *J Am. Med. Assoc.* **249**: 751-757.

Devine JC, Rogers SN, McNally D, Brown JS, Vaughan ED. 2001. A comparison of aesthetic, functional and patient subjective outcomes following lip-split mandibulotomy and mandibular lingual releasing access procedures. *Int. J. Oral Maxillofac. Surg.* **30:** 199-204.

Dhillon RS, Palmer BV, Pittam MR, Shaw HJ. 1982. Rehabilitation after major head and neck surgery - the patients' view. *Clin. Otolaryngol.* **7**, 319-324.

Dropkin MJ. 1979. Compliance in postoperative head and neck patients. *Cancer Nursing*, **2:** 379-384.

Dropkin MJ, Malgady RG, Scott DW, Oberst MT, Strong EW. 1983. Scaling of Disfigurement and Dysfunction in Postoperative Head and Neck Patients. *Head and Neck Surgery*, **6:** 559-570.

Dropkin MJ. 1999. Body Image and Quality of Life After Head and Neck Cancer Surgery, *Cancer Practice*, **7**(6): 309-313.

Dropkin MJ. 2001. Anxiety, Coping Strategies, and Coping Behaviours in Patients Undergoing Head and Neck Cancer Surgery, *Cancer Nursing*, **24**(2): 143-148.

Droughton ML. 1990. Head and neck carcinomas. *J. Palliative Care*, **6**(4), 43-46.

Fallowfield LJ, Baum M, Maguire GP. 1987. Addressing the psychological needs of the conservatively treated breast cancer patient: Discussion paper. *Journal of the Royal Society of Medicine,* **80:** 696-700.

Foss AJE, Lamping DL, Schroter S, Hungerford J. 2000. Development and validation of a patient based measure of outcome in ocular melanoma, *British Journal of Ophthalmology*, **84:** 347-351.

Freedlander E, Espie CA, Campsie L, Soutar DS, Robertson AG. 1989. Functional implications of major surgery for intraoral cancer. *Br. J. Plastic Surg.*, **42:** 266-269.

Gamba A, Romano M, Grosso IM, Tamburini M, Cantu G, Molinari R, Ventafridda V. 1992. Psychosocial adjustment of patients surgically treated for head and neck cancer. *Head and Neck*, **14:** 218-223.

Harris V, Sandridge AL, Black RJ, Brewster DH, Gould A. 1998. *Cancer registration statistics Scotland 1986-1995*. Edinburgh: ISD Scotland Publications.

Hart P.M, Chakravarthy U, Stevenson MR. 1998. Questionnaire-based survey on the importance of quality of life measures in ophthalmic practice. *Eye,* **12:** 124-126.

Hassan SJ, Weymuller EA. 1993. Assessment of quality of life in head and neck patients. *Head and Neck*, **15:** 485-496.

Heidrich SM, Forsthoff CA, Ward SE. 1994. Psychological adjustment in adults with cancer: the self as a mediator. *Health Psychology,* **13**(4): 346-353.

Higgins ET. 1987. Self-Discrepancy: A theory relating self and affect. *Psychological review*, **94**(3): 319-340.

Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. 2000. Reliability and Validity of an Observer-Rated Disfigurement Scale for Head and neck cancer patients. *Head and Neck*, **22**: 132-141.

Kennedy L. 2000. My Eye Cancer Odyssey. Praxis Post.

Kleinstein RN, Lehman HF. 1977. *American Journal of Ophthalmic Physiology*, **54**(1): 49-51.

Koster META, Bergsma J. 1990. Problems and Coping Behaviour of Facial Cancer Patients. *Soc. Sci. Med.* **30**(5): 569-578.

Krouse JH, Krouse HJ, Fabian RL. 1989. Adaptation to Surgery for Head and Neck Cancer, *Laryngoscope*, **99**: 789-794.

Kwok HCK, Morton RP, Chaplin JM, McIvor NP, Sillars, HA. 2002. Quality of life after parotid and temporal bone surgery for cancer. *Laryngoscope*, **112:** 820-833.

Linberg JV, Tillman WT, Allara RD. 1988. Recovery after loss of an eye. *Ophthalmic plastic and reconstructive surgery*, **4**(3): 135-138.

Lockhart JS. 1999. Nurses' perceptions of head and neck oncology patients after surgery: severity of facial disfigurement and patient gender. *ORL-Head and Neck Nursing* **17**(4): 12-25.

MacMahon KMA, Lip GYH. 2002. Psychological Factors in Heart Failure: A review of the literature. *Archives of Internal Medicine*, **162:** 509-516.

McQuellon RP, Hurt GJ. 1997. The Psychosocial Impact of the Diagnosis and Treatment of Laryngeal Cancer. *Otolaryngologic Clinics of North America*, 30(2): 231-241.

Million RR, Cassisi NJ, Clark JR. 1989. Cancer of the head and neck. In: Devita, V., Hellman, S. and Rosenberg, S. A. (Eds.). *Cancer: principles and practices. 3rd Edition.* Philadelphia: JB Lippincott.

Monga U, Tan G, Ostermann HJ, Monga TN. 1997. Sexuality in Head and Neck Cancer Patients. *Arch Phys Med Rehabil.* **78:** 298-304.

Morris J. 1994. Widening Perspectives: Quality of Life as a Measure of Outcome in the Treatment of Patients with Cancers of the Head and Neck. *Oral Oncol. Eur. J. Cancer*, **30B**(1): 29-31.

Morton RP, Davies ADM, Baker J, Baker GA, Stell, PM. 1984. Quality of life in treated head and neck cancer patients: A preliminary report. *Clin. Otolaryngol.* **9:** 181-185.

Moy CS, Melia MM. 1999. Quality of Life assessment in the Collaborative Ocular Melanoma Study: Design and Methods COMS-QOLS Report No. 1. *Ophthalmic Epidemiology*, **6**(1): 5-17.

Owen C, Watkinson JC, Pracy P, Glaholm, J. 2001. The psychosocial impact of head and neck cancer. *Clin. Otolaryngology*, **26**(5): 351-356.

Petrucci RJ, Harwick RD. 1984. Role of the psychologist on a radical head and neck surgical service team. *Professional psychology: Research and Practice*, **15**(4): 538-543.

Rogers SN. 2001. Reflections on: Psychology and Head and Neck Cancer. *Br. J. Oral Maxillo. Surg.* **39:** 346-347.

Rubin PA, Popham J, Rumelt S, Remulla H, Bilyk JR, Holds J, Mannor G, Maus M, Patrinely JR. 1998. Enhancement of the cosmetic and functional outcome of enucleation with the conical orbital implant. *Ophthalmology*, **105**(5): 919-925.

Seddon JM, Gragoudas ES, Albert DM. 1985. Comparison of survival rates for patients with uveal melanoma after treatment with proton beam irradiation. *American Journal of Ophthalmology*, **99:** 282-290.

Shapiro PA, Kornfeld DS. 1987. Psychiatric Aspects of Head and Neck Cancer Surgery. *Psychiatric Clinics of North America*, **10**(1): 87-100.

Sisley K. 1999. Posterior Uveal Melanoma. *Atlas of Genetics and Cytogenetics in Oncology and Haematology.*

Strauss RP. 1989. Psychosocial Responses to Oral and Maxillofacial Surgery for Head and Neck Cancer. *J. Oral Maxillofac. Surg.* **47:** 343-348.

Trunc M, Char D, Kroll SJ. 1997. Uveal melanoma therapies: quality of life effects. *Eyenet,* **16**.

Turns D, Sands RG. 1978. Psychological problems of patients with head and neck cancer. *J Prosthetic Dentistry*, **39**(1): 68-73.

van Doorne JM, van Waas MAJ, Bergsma J. 1994. Facial Disfigurement after Cancer Resection: A Problem with an Extra Dimension. *J. Invest. Surg.* **7:** 321-326.

Webb B. 1990. Mutual support for families of children with eye cancer. *Child: care health and development*, **16**(5): 319-329.

West DW. 1977. Social adaptation patterns among cancer patients with facial disfigurations resulting from surgery. *Arch Phys Med Rehabil*, **58:** 473-479.

White CA. 2000. Body image dimensions and cancer: A heuristic cognitive behavioural model. *Psycho-Oncology,* **9:** 183-192.

Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. 2001. The prevalence of psychological distress by cancer site. *Psycho-Oncology*, **10:** 19-28.

LIST OF TABLES AND FIGURES

List of Tables

		Pages
Table 1.	Quality assessment guidelines.	**58**
Table 2.	Summary of studies examining aspects of appearance change in eye cancer patients.	**59**
Table 3a.	Summary of head and neck cancer studies investigating the impact of disfigurement on a specified outcome.	**60-63**
Table 3b.	Summary of studies assessing appearance related quality of life in head and neck cancer patients.	**64-66**

List of Figures

		Pages
Figure 1.	Anatomy of the eye relevant to eye cancer.	**67**

Table 1 – Quality assessment guidelines[1] (based on MacMahon and Lip, 2002).

1a	Prospective, longitudinal studies with sufficient patient numbers, well matched groups and well validated measurement instruments.
1b	Prospective, longitudinal studies with low patient numbers, but with well-matched groups and well-validated measurement instruments.
2a	Cross sectional studies with sufficient patient numbers, well matched groups and well validated measurement instruments.
2b	Cross sectional studies with low patient numbers, but with well matched groups and well validated measurement instruments.
3a	Prospective, longitudinal studies with sufficient patient numbers, but poorly matched groups and/or less well validated instruments.
3b	Prospective, longitudinal studies with low patient numbers, poorly matched groups and/or less well validated instruments.
4a	Cross sectional studies with sufficient patient numbers, but poorly matched groups and/or less well validated instruments.
4b	Cross sectional studies with low patient numbers, poorly matched groups and/or less well validated instruments.
5a	Prospective, longitudinal studies with sufficient patient numbers, but no groups and/or less well validated instruments.
5b	Prospective, longitudinal studies with low patient numbers, no groups and/or less well validated instruments.
6a	Cross sectional studies with sufficient patient numbers, but no groups and/or less well validated instruments.
6b	Cross sectional studies with low patient numbers, no groups and/or less well validated instruments.

[1]Classification developed for studies other than Randomised Controlled Trials (RCTs).

Table 2: Summary of studies examining aspects of appearance change in eye cancer patients

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Bunston *et al.* (1994)	Cross-sectional.	6a	Adult outpatients with a diagnosis of primary ocular melanoma (n= 96). Inclusion criteria: Patients scheduled to receive treatment, currently receiving treatment, or being followed up.	Male n=43, Female n= 53. Mean age =57.9 years. Treatment: surgery only n=26, radiation only n=47, Surgery and radiation n=15, Observation n=8. Mean time since diagnosis = 4.2 yrs.	In house measure of 'Expressed needs' developed and evaluated in first (qualitative) phase of study to establish non-medical concerns of patients in 14 domains including a domain for 'self image'.	38 patients reported concern regarding their self-image.	No groups. Non-validated measure. Did not elaborate on what patients' concern in relation to self image was.
Brandberg *et al.* (2000)	Cross-sectional.	4a	Adult patients with Posterior Uveal Melanoma (n=78). Group 1: Those treated with ruthenium plaque radiotherapy (n=32). Group 2: Those treated with enucleation (n=46).	Group 1: Male n=17, Female n= 15. Group 2: Male n=21, Female n= 25. Overall group mean age: Male = 64 years, Female = 63 years.	In house measure: 'Eye Symptom Questionnaire'.	A higher percentage of those who were treated with enucleation had problems with appearance during the first year after treatment (54.6%), compared to those treated with ruthenium plaque therapy (13.2%).	Measure not adequately validated and contains only two appearance items. Investigations were not based on any definition, theory or model of body image.

Table 3a: Summary of head and neck cancer studies investigating the impact of disfigurement on a specified outcome

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
West (1977)	Cross-sectional.	6a	Adult head and neck cancer post-operative outpatients (n=152). All participants were required to be 65 years of age or younger due to work being a measure of adjustment. All patients were required to have a visible disfigurement.	Male =81.5%, Female = 18.5% . Mean age =58.4 years. 20% had had surgery less than a year before the study, 10% 1-2 years before the study, 33% 2-5 years before the study and 36% more than 5 years before the study	In-house social adaptation instrument to assess how well each individual had adapted to their change in appearance in fourteen different areas.	86.2% had adapted "very well" to their changed appearance. 11.8% had adapted "quite well" to their changed appearance. 2.0% had adapted "poorly" to their changed appearance.	No groups. Disfigurement was deemed as being present without the use of a scale. Patients were not asked about their body image. Attributing successful adaptation to acceptance of appearance change appears to be have been done arbitrarily without any statistical measures.
Dropkin (1979)	Cross-sectional.	6b	Males with head and neck cancer (n= 10).	None reported.	None.	It was concluded that the more disfigured the patient was post-operatively, the less time he spent voluntarily out of his room. The authors concluded that this suggests that social interaction lessens as deformity becomes more pronounced.	No groups, low numbers males only. Each patient was assigned a number representing degree of deformity, but no further reference to what this number meant. Assumes those undergoing surgery for the first time would sustain greatest impact on their body image. There was no theory of body image.

Table 3a (cont.): Summary of head and neck cancer studies investigating the impact of disfigurement on a specified outcome

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Baker (1992)	Cross-sectional.	6a	Adult head and neck cancer outpatients (n= 51). Inclusion criteria: Patients who were disease free, stage II or greater who were at least 6 months post-treatment.	Male n=37, Female n= 14. Mean age =60 years. Disease free time ranged from 7-60 months.	Disfigurement/Dysfunction scale (Dropkin *et al.*, 1983).	Facial disfigurement was not related to the rehabilitation domains of recreation, sleep, home management and work, but was positively correlated with the 'eating' domain.	No groups & scale not well validated. The investigator decided whether a patient's body image had changed on the basis of observer rated disfigurement. Patients were not asked about their body image. Cannot infer causality from this type of correlational design.
Gamba *et al.* (1992)	Cross-sectional.	4a	Adult outpatients surgically treated for head and neck cancer and free from disease (n= 66). Group 1: Minor disfigurement group (MDG) n=24 (36%). Group 2: Extensive disfigurement group (EDG) n=42 (64%).	Overall Male n=57 (86%), Female n=9 (14%). Mean age 54.1 years Mean time elapsed since surgery 3.2 years.	Degree of disfigurement (i.e. extensive or minor) was determined by outpatient physician. In house battery of questions requiring 'yes/no' answers in relation to post-surgical aspects of self-image and body image. Open remarks were also collected.	Group 1: (MDG) 25% had a changed self image. Group 2: (EDG) 57% had a changed self image.	Degree of disfigurement was determined without the use of a scale. In-house measure not validated at all. Did not define concept of 'self-image', ascertain how it changed, or base it on any theory. Over-represented by males.

Table 3a (cont.): Summary of head and neck cancer studies investigating the impact of disfigurement on a specified outcome

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Monga *et al.*, (1997)	Cross-sectional.	6a	All head and neck cancer patients treated with radiation therapy (with or without surgery) who had completed treatment at least three months earlier and attended radiation oncology follow-up clinic from January – October 1994 (n=55).	Male n=54, Female n=1. Mean age = 65.1 years. Mean duration since diagnosis = 30.6 months. All patients received radiation therapy and 26 also received surgery.	Disfigurement/Dysfunction scale (Dropkin *et al.*, 1983).	There was a trend towards poorer sexual functioning in patients with extensive disfigurement but this was not significant. 28 patients had no disfigurement. 9 had minor disfigurement. 18 had extensive disfigurement. Patients with extensive disfigurement felt more unattractive and older.	No groups. Appearance measure not well validated. The investigator decided whether a patient's body image had changed on the basis of observer rated disfigurement. There was no definition of body image and patients were not asked about their body image. No significance values given in results section although it seems some type of statistical analysis was performed on data.
Dropkin (1999)	Cross-sectional.	6a	Patients aged 21 years or more with at least 8 years of education who were expected to undergo disfigurative surgery for head and neck cancer (n=117).	Male n=81, Female n= 36. Range of ages was 27 to 86 years (no mean given).	Disfigurement/Dysfunction scale (Dropkin *et al.*, 1983).	Anticipation of disfigurative surgery was associated with low levels of coping effectiveness.	Very unclear – aim of study did not relate to results reported. No groups. Measure not well validated. There was no definition of body image.

Table 3a (cont.): Summary of head and neck cancer studies investigating the impact of disfigurement on a specified outcome

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Dropkin (2001)	Cross-sectional.	6a	Adults about to sustain disfigurement associated with head and neck cancer surgery (n=75).	Male n = 53 (70%), Female n = 22 (30%). Mean age = 61 years.	Disfigurement/Dysfunction scale (Dropkin *et al.*, 1983).	The sample sustained moderate facial disfigurement. Anticipation of disfigurative surgery was associated with high levels of anxiety. Although mean anxiety score decreased over time, there was no significant relationship between degree of disfigurement and anxiety following surgery.	No groups. Appearance measure not well validated. The investigator decided whether a patient's body image had changed on the basis of observer rated disfigurement. There was no definition of body image and patients were not asked about their body image.

Table 3b: Summary of studies assessing appearance related quality of life in head and neck cancer patients

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Dhillon *et al.* (1982)	Cross-sectional.	4b	Adults who had been treated for head and neck cancer who were now disease free and attending follow-up clinics (n = 49). Group 1 Those who had had a laryngectomy (n=35). Group 2 Those who had had a commando procedure (n=14). (A commando procedure was defined as excision of a primary tumour in the oral cavity combined with radical neck dissection and flap repair).	Group 1 Male n=31, Female n= 4. Mean age = 65 years. Group 2 Male n=7, Female n= 7. Mean age = 70 years.	A six page in-house questionnaire assessing degree of disability in five areas including 'cosmetic' completed by the patient.	Group1 Only 1 patient (3%) felt their facial appearance change was 'severe'. Group 2 4 patients (29%) felt their facial appearance change was severe, and a further 4 (29%) felt 'moderately' disfigured'.	Low patient numbers. Non-validated measure - contents and detailed scoring not reported. Hence, difficult to interpret what they were actually measuring. Investigations were not based on any definition, theory or model of body image.
Morton *et al.* (1984)	Cross-sectional.	4b	Adult patients with head and neck cancer treated within the past three years and with no evidence of disease for at least 6 months (n=48). Group 1 Radiotherapy alone (n=19). Group 2 Salvage surgery after failed radiotherapy (n=17). Group 3 Surgery alone (n=12).	Male = 100%. All aged over 60 years and retired from employment.	Specially constructed, in-house 'Body Satisfaction Scale' on which patients were asked to rate satisfaction with the appearance of named parts of the body using a four-point scale.	Overall 53% of patients felts that their looks had been affected. Group 2 had the highest body dissatisfaction followed by group 3. These differences were reported as statistically significant.	Non-validated measure - contents and detailed scoring not reported. Hence, difficult to interpret what they were actually measuring. Caution should be taken when accepting statistically significant differences as numbers in each group were quite low. Limited to male, retired patients so limited generalisability of findings.

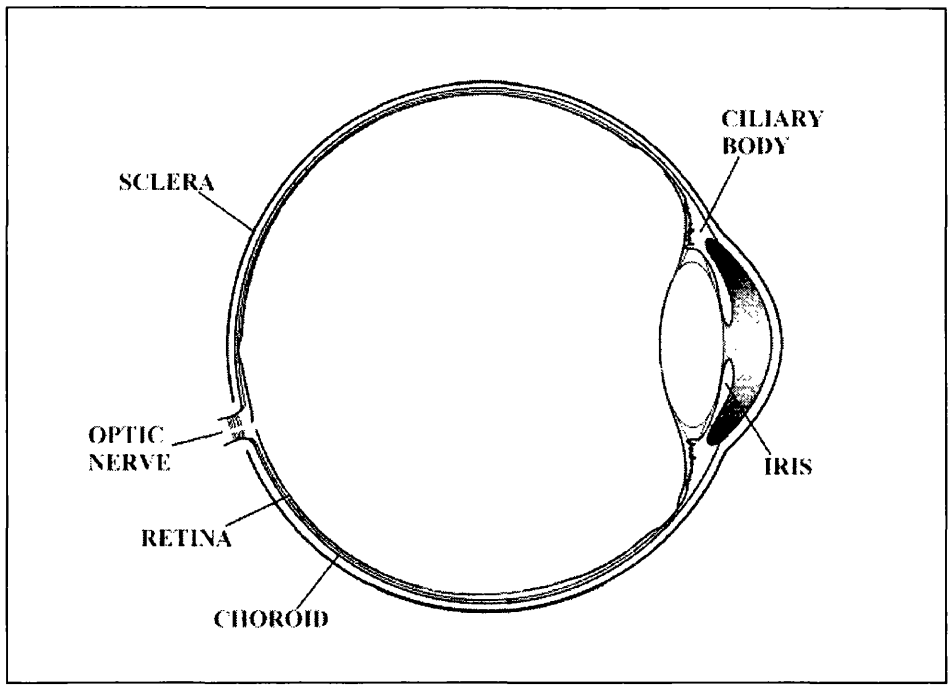
Table 3b (cont.): Summary of studies assessing appearance related quality of life in head and neck cancer patients

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Freedlander *et al.* (1989)	Cross-sectional.	4b	Adult intraoral cancer patients who had had surgery with or without postoperative radiotherapy (n=41). Group 1: Patients who had had a radical flap procedure (n=27). Group 2: Patients who had had a pedicled flap procedure (n=14).	Overall 27 males and 14 females Mean age 64 years Time elapsed since operation ranged from 6 months to 10 years	In house interview to establish any embarrassment or difficulties the patients had experienced in relation to their appearance.	Analysis showed no significant differences between the groups. Overall 20-25% reported moderate to severe embarrassment in relation to appearance, and 15% of men compared to 43% of women were concerned about appearance.	Low patient numbers. Non-vaildated measure and contents of the measure were not reported.
Krouse *et al.* (1989)	Prospective longitudinal. Patients assessed at three time points: Time 1 Preoperatively. Time 2 Three months post-surgery. Time 3 Nine to twelve months following discharge.	5b	Adults who had undergone surgery for head and neck cancer (n= 33).	Male n=30, Female n= 3. Mean age = 58 years.	Body Image Questionnaire (Berscheid *et al.*, 1972).	95% of patients rated appearance average to excellent pre-operatively and this percentage remained constant post-operatively over one year. The authors therefore concluded that body image and appearance did not contribute significantly to postoperative adjustment.	No groups. Low numbers and the sample was over-represented by males. The body image measure used has not been validated and is not based on any psychological theory of body image.

Table 3b (cont.): Summary of studies assessing appearance related quality of life in head and neck cancer patients

Investigator(s)	Design	Study Quality	Target Group Description	Sample Characteristics	Body Image / Appearance Measure(s)	Outcome	Study Limitations
Devine *et al.* (2001)	Cross-sectional.	4b	Adult patients with previously untreated oral carcinoma (n=20). Group 1: Patients who had had 'lip-split' surgery (n=10). Group 2: Patients who had had 'mandible release' surgery (n=10).	Group 1: Male n=7, Female n=3. Mean age = 59.3 years Group 2: Male n=7, Female n=3. Mean age = 51.9 years	In-house clinician, patient and layperson rated aesthetic assessment of the patient's face and neck following surgery. Patient rated impact of appearance change using the disfigurement questions on UW-QOL (Hassan and Weymuller, 1993).	No statistically significant differences between groups on any of the aesthetic ratings, or on the UW-QOL disfigurement questions. Concluded: No difference in aesthetic outcome between the two techniques.	Low patient numbers. Non-validated in-house aesthetic assessment.
Kwok *et al.* (2002)	Cross-sectional.	4b	Adults with cancer of the parotid gland or temporal bone and who had received treatment in the last 15 years (n=23). Group 1: Patients who had had temporal bone resection (TBR) (n=10). Group 2: Patients who had had parotidectomy and radiation (P+RT) (n=13).	Group 1: (TBR) Male =73%, Female = 27% Mean age = 84 years. Mean years since treatment = 4.5. Group 2: (P+RT) Male = 92% Female = 8% Mean age = 71 years. Mean years since treatment = 3.8.	Patient rated the impact of appearance change using two questions, one each from: EORTC QLQ-H&N35 (Bjordal *et al.*, 1994) & UW-QOL (Hassan and Weymuller, 1993).	TBR group had lower appearance quality of life than P+RT group on UW-QOL item. There was no difference between groups on the EORTCQLQ-H&N35 item for appearance QOL. There was only a moderate correlation between the two appearance QOL items.	Low patient numbers. Although the measures themselves are well-validated, outcomes were based on single items, the contents of which were not specified.

Figure 1. – Anatomy of the eye relevant to eye cancer



3. MAJOR RESEARCH PROJECT PROPOSAL

The Importance of Facial Appearance in Patients with Eye Cancer

Prepared in accordance with the D. Clin. Psy. Handbook guidelines and those issued by the West Ethics Committee.

The Importance of Facial Appearance in Patients with Eye Cancer

Applicant:

Nicola J. Brown
Trainee Clinical Psychologist
Dept. of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Supervisor:

Dr Craig A. White
Cancer Research UK Fellow in Psychosocial Oncology
Dept. of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

SUMMARY

There are a limited number of studies relating to body image and cancer and they have tended to examine it with unsophisticated methods. Cash and Pruzinsky (1990), however, defined body image as a more complex construct, which encompasses a person's perceptions, thoughts, feelings, and actions. This research aims to further the understanding of the impact of eye cancer on a patient's body image by applying the 'investment in body ideals' component of the model proposed by White (2000).

Investment in body ideals is determined by i) the degree to which a person has an investment in the changed body feature or features, and ii) the presence of a discrepancy between ideal / self and actual / self. However, it is also proposed that receiving a diagnosis of cancer may overshadow concerns over appearance when individuals are more concerned with survival than cosmetics. Therefore, investment in facial appearance may differ between patients with eye cancer and those with other, non-life threatening eye diseases such as thyroid eye disease (TED). These differences will be explored in this study using a modified version of the Body Image Ideals Questionnaire (BIQ) (Szymanski and Cash, 1995), specifically addressing facial appearance, the BIQ-face, plus a modified version of the Appearance Schemas Inventory (ASI) (Cash and Labarge, 1996), specifically addressing facial appearance, the ASI-face, and the Pictorial Representation of Illness and Self Measure (PRISM) (Buchi and Sensky, 1999).

The power calculation is based on normative data for the ASI (Cash and Labarge, 1996). Using Cohen's (1992) tables, in the present study 26 participants would be required in each group to detect significant differences ($p<0.05$) on an independent samples t-test or ANOVA with power 0.8 and a large Effect Size.

In addition to furthering the understanding of the impact of eye cancer on a patient's body image, the research will also be of specific use to the Consultant Ophthalmologist, by helping inform his practice when dealing with issues involving a patient's concerns about facial appearance following surgery.

INTRODUCTION

Appearance change, body-image, and cancer

There are a limited number of studies relating to appearance change and cancer, with the majority of the research being carried out with breast cancer patients. A small number of studies have been carried out with facial cancer patients. Only two papers were identified that had sought to measure body image as a principal outcome in an eye cancer population. In head and neck cancer, only thirteen studies had aimed to systematically evaluate body image / appearance as a principal outcome and the quality of this research was generally poor. This research treated body image as a simplistic construct and examined it with unsophisticated methods. However, Cash and Pruzinsky (1990), have defined body image as a more complex construct, which encompasses a person's perceptions, thoughts, feelings, and actions.

The Self and Self-Discrepancy Theory

Reber (1995) defines the 'self' as "one's concept of oneself in as complete and thorough a description as is possible for one to give". Similarly Curbow *et al.* (1990) define the term as "a collection of self-representations". Markus and Wurf (1987) further describe several dimensions that characterise and differentiate self-representations. For example, 'valence' (i.e. positive or negative) and 'time orientation' (i.e. past, present, future). In this way, if a cancer patient has a self-concept that includes a representation of the self on, say a 'physical strength' dimension, this allows this to be further characterised for that person as, for example, 'negative' and 'current'.

It can be seen that both of the above definitions propose that the 'self' is multi-faceted. Rosenberg (1977) proposed that these multiple aspects develop through both internal self-evaluations and interpersonal experiences. Thus, it is suggested that aspects of the self are dynamic, as in response to external events, different aspects of may be changed or modified. It has also been proposed that some self-representations are "core", while others are peripheral (Curbow *et al.*, 1990).

In Higgins' (1987) Self-Discrepancy, two of the components that constitute the self are *ideal* / self and *actual* / self. Ideal / self refers to the aspirations as to who one could potentially be, whereas actual / self refers to conceptions as to who one really is. Higgins (1987) proposes that the greater the magnitude and accessibility of a particular type of self-discrepancy, the more its owner will experience the kind of discomfort associated with it. Individuals are therefore motivated to achieve a match between their ideal / self and actual / self because a discrepancy would result in psychological distress.

Specifically, if a person possesses a discrepancy between ideal / self and actual / self, the current state of his or her attributes does not match the ideal state that he or she hopes or wishes to attain. Higgins (1987) proposes that an ideal / actual self-discrepancy therefore represents the general psychological situation of the absence of positive outcomes (i.e. non-obtainment of one's hopes and desires). This predicts vulnerability to dejection related emotions such as disappointment and dissatisfaction, as in psychological analyses of these emotions they have been described as being associated with discrepancy from hopes, desires or ideal (e.g. Abelson, 1983;Carver and Ganellen, 1983).

A diagnosis of cancer is particularly threatening to the self because it is associated with both fear of pain and death due to the disease, and fears of painful and debilitating and possibly disfiguring treatment. Receiving a diagnosis of cancer is therefore a particularly potent motivation for engaging in adjustments related to the self (Curbow *et al.*, 1990). Self-discrepancy theory proposes, that in response to external threatening events (such as a diagnosis of cancer), aspects of the self are altered in an attempt to maintain an ideal / self - actual / self match, which reduces psychological distress and enhances psychological adjustment.

Investment

Cash and Szymanski (1995) highlighted that previous body image research has tended to regard all physical attributes as if they were of equal importance. They proposed that it is the degree to which someone places *importance* on a perceived ideal / actual self-discrepancy that is important, and not merely the discrepancy being present. Thus, an ideal / actual self-discrepancy of major importance (i.e. one that has high *investment*) will have a significant psychological impact, being equivalent to having multiple ideal / actual self-discrepancies that are each associated with lesser degrees of importance. By combining the concept of investment with Higgins' (1987) self-discrepancy theory, they were able to account for the differential degrees of importance that are placed on physical features by different people.

Investment in body ideals

White (2000) proposed a heuristic cognitive behavioural model of body image and cancer. One component of the model is 'investment in body ideals', which incorporates Cash and Szymanski's (1995) concept of 'investment', and Higgins'

(1987) 'self-discrepancy theory'. Investment in body ideals is determined by i) the degree to which a person has an investment in the changed body feature or features, and ii) the presence of an ideal / actual self-discrepancy. Therefore, cancer patients with high levels of personal investment in discrete physical attributes should experience more negative psychological consequences following changes in that attribute than patients experiencing similar objective changes, but who have less personal investment in the attribute.

However, receiving a diagnosis of cancer, which is a life threatening disease, may overshadow concerns over appearance when individuals are more concerned with survival than cosmetics (Fallowfield *et al.*, 1987, Pozo *et al.*, 1992). In contrast, survival is unlikely to be the main concern for those individuals whose facial appearance may also change as a result of surgery, or from treatment, but whose diagnosis is not life threatening (e.g. thyroid eye disease (TED) patients). As TED is not life threatening, people with TED may be less concerned about whether they are going to die.

Given that facial appearance has changed, it is likely that ideal / actual self-discrepancies relating to the face exist in people with eye disease. However, investment in facial appearance is likely to differ between those patients with eye cancer and those with other eye diseases such as Thyroid Eye Disease (TED). This will be investigated by applying the 'investment in body ideals' component of White's (2000) model, which has not yet been empirically tested.

Hypotheses

1. Participants with eye cancer and TED will have higher levels of psychological distress compared to control participants.
2. Levels of ideal / actual self-discrepancies relating to facial appearance will be higher in participants with eye disease (cancer and TED patients) compared to control participants.
3. Facial appearance will be more important to TED patients compared to eye cancer patients.
4. Patients with eye cancer will be more concerned about their illness than their facial appearance and patients with TED will be more concerned about their facial appearance than their illness.

METHODOLOGY

Participants

Common inclusion criteria for the eye cancer and thyroid eye disease groups

- Adult patients who have had their vision corrected following surgery (most likely by spectacles).

Additional inclusion criteria for the eye-cancer group

- Adult patients who have a confirmed diagnosis of eye cancer and are aware that this is their diagnosis.

Additional inclusion criteria for the TED group

- Adult patients who have a confirmed diagnosis of Thyroid Eye Disease (TED) and are aware that this is their diagnosis.

Inclusion criteria for the Control group

- Controls will be taken from a convenience sample of willing adult volunteers.
- Controls will have normal vision or have had their vision corrected to be normal by either spectacles or contact lenses.

Common exclusion criteria for all groups

- People with a previous diagnosis of eye disease (i.e. for Eye Cancer and TED groups, this must be the first time they have had an eye disease, and controls must not have had an eye disease before).

Additional exclusion criteria for the Eye-Cancer group

- People with a previous diagnosis of cancer.

Procedure

Eye-cancer (Eye Cancer group), and thyroid eye disease (TED group) patients referred to the Tennent Institute of Ophthalmology service based at the Gartnavel General Hospital in Glasgow will be recruited for the study. Participant gender will be matched to the gender distribution that occurs in each eye disease. Participants will be recruited through the Consultants and medical staff involved in the service. Willing

potential participants will be contacted by the principal investigator and to identify if they meet the inclusion criteria. It will be made clear that participation is voluntary and they can withdraw from the research at any time. The nature and procedure of the study will be explained to suitable willing participants and an information sheet will be provided (Appendix 3.1). Opportunities will be given for participants to ask any questions and they will then be asked to sign the consent form (Appendix 3.2). They will also be asked to decide whether or not to consent to existing photographic material being used for illustrative purposes only. This will be on the understanding that all attempts will be made to make the material anonymous. They will receive a copy of this consent form once it has been signed by the Doctor. It is anticipated that only one appointment will be necessary to collect data and each appointment will take approximately 45 minutes to one hour. Control participants will be taken from a 'convenience' sample of the author's family and friends. Willing participants will be asked to complete the following measures:

Measures

Brief Symptom Inventory (BSI) (Derogatis and Melisaraatos, 1983).

This is a familiar 53-item self-report measure of psychological distress. Each item is rated on a 5-point scale of distress from 0 (not at all) to 4 (extremely). The BSI is scored and profiled in terms of nine primary symptom dimensions and three global indices of distress. The Global Severity Index (GSI) will be used in the present study. This is the sum of all items divided by the total number of responses (i.e. 53 when there are no missing responses). The GSI is then converted to standardised score to enable comparison with a relevant reference group. The scale's internal consistency (alpha) ranges from 0.71 to 0.85 and the test-retest reliability (r) ranges from 0.68 to

0.91, indicating acceptable reliability. Convergent validity ranges from 0.92 to 0.98, which is also deemed satisfactory (Croog *et al.*, 1986).

Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).

This is to be used in addition to the BSI as it is very familiar and is widely used. It is a 14-item self-report measure of anxiety (7 items) and depression (7 items). Each item is scored on a four point scale (0, 1, 2, 3). The range of scores is therefore 0-21 for the anxiety subscale, and 0-21 for the depression subscale. Both the Anxiety subscale and the Depression subscale will be computed in the present study. Internal consistency (alpha) ranges from 0.80 to 0.93 for the anxiety subscale and 0.81 to 0.90 for the depression subscale. Test-retest reliability shows a high correlation of 0.8 (r) of up to two weeks (Herrmann, 1997).

In addition, using both the BSI and HADS provides a way of checking the validity of the data provided by comparing that found on each measure independently.

If the scores on the BSI and/or HADS are particularly high these will be discussed with the Consultant and patients wishing to be referred for psychological intervention will be referred to local services via their GP. This will be outlined to patients at the recruitment stage and is also contained in the information sheet.

Appearance Schemas Inventory - (ASI) (Cash and Labarge, 1996) (Appendix 3.3).

This is a 14-item scale designed to assess core beliefs or assumptions about the importance, meaning, and effects of appearance in one's life. Each item is marked on a five point Likert scale, with responses ranging from: "1 = Strongly Disagree", "2 = Mostly Disagree", "3 = Neither Disagree nor Agree", "4 = Mostly Agree" and "5 =

Strongly Agree". The range of mean ASI scores is therefore 1 - 5. Examples of items are:

1. What I look like is an important part of who I am.
2. What is wrong with my appearance is one of the first things that people will notice about me.

The ASI mean for the standardisation sample of 274 female college students was 2.61 (SD = 0.67). The scale's internal consistency (alpha) is 0.84 for college women, indicating acceptable reliability. Convergent and discriminant validity were also deemed satisfactory (Cash and Labarge, 1996).

Appearance Schemas Inventory (Face) – (ASI–face) (Appendix 3.4).

This questionnaire is a modified version of the ASI, developed for this study. The authors stated that each applicable item of the ASI could be been re-written to relate specifically to facial appearance (Cash, personal communication). They also recommended that both original and modified versions be administered, in order that further data for the validated version could be gathered. The ASI and ASI-face can each be completed in less than 5 minutes.

Body Image Ideals Questionnaire - (BIQ) (Szymanski and Cash, 1995) (Appendix 3.5).

This is an 11-item questionnaire designed to assess perceived discrepancy from and degree of investment in personal ideals on multiple physical attributes. Using a four point Likert scale, the BIQ measures *self-discrepancies*, and *investment* of each attribute. The weighted product of these two measurements can also be calculated.

Currently the measure consists of 11 items, with only 2 items relating specifically to the face. For example:

Item 4 A. **My ideal facial features (eyes, nose, ears, facial shape) are**: - (response in the range "0 = Exactly as I am", "1 = Almost as I am", "2 = Fairly unlike me" and "3 = Very unlike me").

B. **How important to you are your ideal facial features?** – (response in the range "0 = Not important", "1 = Somewhat important", "2 = Moderately important" and "3 = Very important")

The following three mean scores are derived from the BIQ:

1. **Mean self-ideal discrepancy score (part a)** (note: 0 scores are first converted to –1):

   Range -1 to +3 (whereby -1 relates to "my ideal is exactly as I am", and, +3 relates to "my ideal is very unlike me").

2. **Mean importance score (part b)**:

   Range 0 to +3 (whereby 0 relates to "my ideal is not important", and, +3 relates to "my ideal is very important").

3. **Mean weighted score (part a multiplied by part b)**:

   Range –3 to +9 (whereby -3 relates to "my ideal is exactly as I am and is very important" - representing *very important congruence*, and, +9 relates to "my ideal is very unlike me and is very important – representing *very important discrepancy.*

This scale's internal consistency (alpha) is 0.82 for college women, indicating acceptable reliability.

Body Image Ideals Questionnaire (Face) – (BIQ–face) (Appendix 3.6).

This questionnaire is a modified version of question 4 of the BIQ, developed for this study. The authors stated that Item 4 (ideal facial appearance) could be expanded so that the individual facial features were assessed separately (Cash, personal communication). They also recommended that both original and modified versions be administered, in order that further data for the validated version could be gathered. The BIQ and BIQ-face can each be completed in less than 5 minutes.

Pictorial Representation of Illness and Self Measure (PRISM) and (PRISM+) (Buchi and Sensky, 1999) (Appendix 3.7).

This measure yields a quantitative measure of Self-Illness Separation (SIS), which is the distance between the centres of two disks, one representing 'Self' and one representing 'Illness' with a range of 0-27cm. The SIS reflects a person's perception of the intrusiveness and controllability of their illness or its symptoms in relation to their life as a whole. PRISM+ is an extension of PRISM using any number of further differently coloured disks. In this study two differently coloured disks will be used: one to represent 'Illness' and one to represent 'Facial Appearance'. These will be used to represent the relative importance of each in relation to 'Self'. This scale's test-retest reliability (r) is 0.95 and its inter-rater reliability (r) is 0.79 indicating acceptable reliability (Buchi *et al.*, in press).

Clinician-rated Facial Appearance change scale (Appendix 3.8).

This is a single item clinician rated nine point Likert scale developed for this study. It is based on the observer-rated disfigurement scale designed by Katz *et al.* (2000) where the inter-rater reliability (r) was 0.91, indicating acceptable reliability. It measures the degree of facial appearance change from "1" (minimal) to "9" (severe) A clinician who has examined the patient on the day they take part will complete this rating scale for each patient.

It was of concern that asking eye disease patients about their facial appearance may increase their anxiety. However, it has been found that the majority of participants in this kind of research do not report undue distress as a result of exposure to emotionally salient material (Fallowfield *et al.*, 1987). In their study, in addition to administering psychological questionnaires to patients with early breast cancer, they also examined the acceptability of these questionnaires from the patient's perspective. Although three patients out of one hundred and two who participated found the interview emotionally upsetting, they also reported that it had been helpful. There were no other negative findings. One hundred patients stated that they would participate in such a study again and many wrote lengthy comments about the cathartic release or insight that the exercise had given them. Thus it is felt that in the present study, participation may have a therapeutic effect on patients who may have few other opportunities to express their emotions in relation to their eye disease.

Power calculation

This study is a preliminary test of a hypothesis and consequently there was no direct comparison study from which to conduct a power calculation. The power calculation is based on normative data for the Appearance Schemas Inventory (ASI) (Cash and Labarge, 1996), where in a sample of 274 college females the mean score was 2.61 (SD = 0.67). In the present study a mean difference score of 1 between groups has been deemed as a clinically significant difference. This is equivalent to 1/0.67 = 1.49 standard deviations (SDs). Using Cohen's (1992) tables, this reflects a large Effect Size and therefore 26 participants would be required in each group to detect significant differences ($p<0.05$) on an independent samples t-test or Analysis of Variance (ANOVA) with power 0.8. It is accepted that there are limitations in basing the calculation for the present study on data for the ASI, as the present study involves both genders and a patient population, and the ASI's population consisted of college females.

Design

Overall the study will utilise a combination of cross-sectional, between and within subjects' designs.

Hypothesis 1

This will use a between subjects design with one factor 'Participant group', having three levels: Eye Cancer, TED, or Control. The three dependent variables will be the

means of the Brief Symptom Inventory (GSI), Hospital Anxiety and Depression Scale (HADS) (Anxiety subscale) and HADS (Depression subscale).

Hypothesis 2

This will use a between subjects design with one factor 'Eye Disease', having two levels (present or not present). The dependent variable will be the mean of the Body Image Ideals Questionnaire-face (BIQ-face) discrepancy scores.

Hypothesis 3

This will use a between subjects design with one factor 'Eye Disease Type', having two levels (TED or Cancer). The first and second dependent variables will be the mean of the BIQ-face importance and weighted scores. The third dependent variable will be the mean ASI-face score.

Hypothesis 4

This will use a 2x2 mixed subjects design. Eye disease type will form the between subjects factor, with two levels (TED or Cancer). Domain will form the within subjects factor, with two levels (Facial Appearance and Illness). The dependent variable will be mean distances in cm between the 'Self' disk and the two domain levels' disks on the PRISM.

Data Analysis

There will be two parts to the data analysis:

1. *Descriptive*

Here demographic information such as age, gender, diagnosis, occupation and marital status, will be described. The means and standard deviations of the data obtained will be tabulated / described here.

2. *Analytical*

Hypotheses 1, 2 and 3 will be analysed using independent samples statistical methods. For hypothesis 1 the following means of the three groups (Eye Cancer, TED and Control) will be compared: HADS anxiety and depression subscales and Brief Symptom Inventory Global Severity Index (GSI). For hypothesis 2 the BIQ-face mean discrepancy scores for the two groups (Eye Disease and Control) will be compared. For hypothesis 3 the BIQ-face mean importance and weighted scores for the two Eye Disease groups will be compared and the mean ASI-face scores for the two groups will also be compared.

Hypothesis 4 will be analysed using both within and independent samples statistical methods. Self-Illness Separation and Self-Facial Appearance Separation will be analysed between and within the two Eye Disease groups (Eye Cancer and TED).

Practical Applications

This research will further the understanding of the impact of eye cancer on a patient's body image. The research will also be of specific use to the Consultant Ophthalmologist to help inform his clinical decision making and general practice when dealing with issues involving patients' concerns about facial appearance following surgery.

Timescale

Data Collection: September 2001 – March 2002.

Statistical Analysis: March 2002 – April 2002.

Write up: May 2002 – July 2002.

Ethical Approval

This proposal was submitted to the West Ethical Committee on 18th June 2001 and received approval on 26th July 2001 (see Appendix 3.9 letter of approval).

References

Abelson RP. 1983. Whatever became of consistency theory? *Personality and Social Psychology Bulletin*, **9**: 37-54.

Buchi S, Sensky T. 1999. PRISM: Pictorial Representation of Illness and Self Measure. *Psychosomatics,* **40**: 314-20.

Buchi S, Buddeberg C, Kaghofer R, Russi EW, Brandli O, Schlosser C, Stoll T, Villiger PM, Sensky T. (in press). Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure) - a brief method to assess suffering.

Carver CS, Ganellen RJ. 1983. Depression and components of self-punitiveness: High standards, self-criticism and overgeneralisation. *Journal of abnormal psychology*, **92**: 330-337.

Cash TF. 2001. Personal communication.

Cash TF, Pruzinsky T. (Eds.) 1990. *Body images: Development, deviance, and change*. New York: Guilford Press.

Cash TF, Szymanski ML. 1995. The development and validation of the Body Image Ideals Questionnaire. *Journal of Personality Assessment* **64**(3): 466-477.

Cash TF, Labarge AS. 1996. Development of the Appearance Schemas Inventory: A New Cognitive Body-Image Assessment. *Cognitive Therapy and Research*, **20**(1): 37-50.

Cohen J. 1992. A Power Primer. *Psychological Bulletin,* **112:** 155-159.

Croog SH, Levine S, Testa MA. 1986. The effects of anti-hypertensive therapy on quality of life. *New England Journal of Medicine*, **314**(26): 1657-1664.

Curbow B, Somerfield M, Legro M, Sonnega J. 1990. Self-concept and cancer in adults: Theoretical and methodological issues. *Social Science and Medicine* **31**: 115-28.

Derogatis LR, Melisaraatos N. 1983. The Brief Symptom Inventory (BSI): An introductory report. *Psychological Medicine,* **13**: 595-606.

Fallowfield LJ, Baum M, Maguire GP. 1987. Addressing the psychological needs of the conservatively treated breast cancer patient: Discussion paper. *Journal of the Royal Society of Medicine*, **80:** 696-700.

Herrmann C. 1997. International experiences with the hospital anxiety and depression scale - a review of validation data and clinical results. *Journal of Psychosomatic Research*, **42**(1): 17-41.

Higgins ET. 1987. Self-Discrepancy: A theory relating self and affect. *Psychological review*, **94**(3): 319-340.

Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. 2000. Reliability and validity of an observer-rated disfigurement scale for head and neck cancer patients. *Head and neck* **22**: 132-41.

Markus H, Wurf E. 1987. The dynamic self-concept: a social psychological perspective. *A. Rev. Psychol.* **38**: 299-337.

Pozo C, Carver CS, Noriega V. 1992. Effects of mastectomy versus lumpectomy on emotional adjustment to breast cancer: A prospective study of the first year post surgery. *Journal of Clinical Oncology,* **10**: 1292-1298.

Reber AS. 1995. *Dictionary of psychology (2nd Edition).* London: Penguin.

Rosenberg M. 1977. *Conceiving the self.* New York: Basic Books.

Szymanski ML, Cash TF. 1995. Body image disturbances and self-discrepancy theory: expansion of the Body Image Ideals Questionnaire. *J. Soc. Clin. Psychology.* **14**(2): 134-146.

White CA. 2000. Body image dimensions and cancer: A heuristic cognitive behavioural model. *Psycho-oncology,* **9**: 183-192.

Zigmond AS, Snaith RP. 1983. The Hospital Anxiety and Depression Scale, *Psychiatrica Scandinavica,* **67**: 361-370.

4. MAIN RESEARCH PROJECT PAPER

The Importance of Facial Appearance in Patients with Eye Cancer

Prepared for submission to *Psycho-Oncology*
(See Appendix 4.1 for notes to contributors).

The Importance of Facial Appearance in Patients with Eye Cancer

Nicola J. Brown
Department of Psychological Medicine
University of Glasgow, Glasgow, G12 0XH

SUMMARY

Purpose: To determine investment in body ideals in relation to facial appearance in patients with eye cancer by applying White's (2000) heuristic cognitive behavioural model of cancer. Also to ascertain psychosocial functioning and the relative importance of illness and facial appearance in eye cancer patients' lives.

Patients and methods: Outpatients referred to the Tennent Institute of Ophthalmology service, Gartnavel General Hospital, Glasgow were recruited for the study. A cross-sectional design was used. Eye cancer patients were the principal patient group (n=44), Thyroid Eye Disease (TED) patients were the eye disease comparison group (n=44) and a convenience sample of non-eye disease participants (n=75) acted as controls. Participants completed the Hospital Anxiety and Depression Scale (HADS), Brief Symptom Inventory (BSI), Body Image Ideals Questionnaire (BIQ), BIQ-face, Appearance Schemas Inventory (ASI), ASI-face and Pictorial Representation of Illness in Self-Measure (PRISM). A clinician-rated appearance change scale was also completed for each patient.

Results: TED patients were more distressed than eye cancer patients and controls. Small discrepancies between ideal and actual self in relation to facial appearance were present in all groups, although eye cancer patients were significantly less concerned about these discrepancies than TED patients. The hypothesis that facial appearance would be more important for TED patients compared to Eye Cancer patients was supported by outcomes from the ASI-face and the BIQ-face weighted score. Eye cancer patients had minimal facial appearance change and TED patients moderate. Although both groups assigned their illness and facial appearance as equally important, the TED group demonstrated a larger burden of suffering due to their illness and facial appearance than eye cancer patients on the PRISM.

Conclusions: These results offer initial support for the investment in body ideals component of White's (2000) model, however, further research involving a larger objective change in appearance due to cancer is required. It is also proposed that this model could feasibly be applied to the study of other illnesses in which there have been appearance changes. The expectations of the outcome of PRISM based on assumptions about disease involving generic aspects of illness were incorrect. It is suggested that perhaps the concept of "Illness" associated with PRISM was too global for patients to access the cancer specific issue of survival in this study. Limitations of the study and recommendations for future research are provided.

1. INTRODUCTION

Cancer of the eye and adnexa[1] is a rare form of cancer and is the only ocular disease that directly threatens life (Kleinstein and Lehman, 1977). It is associated with a five-year mortality rate of 35% and a ten-year mortality rate of nearly 50% (Cruickshanks *et al.*, 1999; Brandberg *et al.*, 2000). Factors that influence treatment choice in eye cancer patients include size, extent and location of the tumour. Patients who have medium or large sized tumours that are growing can be managed with either radiotherapy or local resection of the tumour. Patients who have large tumours that have produced severe visual loss are more likely to be managed by enucleation (removal of the eye) followed by a prosthetic orbital implant (Sisley, 1999). No differences in survival have been reported between these methods of treatment (Seddon *et al.*, 1985).

There is evidence to suggest that there is a high prevalence of psychological disorder in cancer patients. For example, Derogatis *et al.* (1983) found that, using DSM-III criteria (American Psychiatric Association, 1980), 47% of cancer patients received a diagnosis. Of these patients, 85% were experiencing a disorder with depression or anxiety as the central symptom. A more recent study of the prevalence of psychological distress of cancer patients reported an overall rate of distress of 20% (Zabora *et al.*, 2001). The authors concluded that there is a great need to identify high-risk patients through psychosocial screening in order to provide early intervention. Thus, given the distress experienced by many cancer patients, the importance of clinicians' understanding of psychosocial adjustment to cancer has been emphasised (Brennan, 2001).

[1] For the purposes of this research, "eye cancer" will be used to refer to "eye and adnexa cancer", whereby adnexa are the adjoining anatomical parts of the eye.

Eye cancer patients like other cancer patients are therefore at risk of developing psychological disorders. In addition to having to cope with a life threatening diagnosis, they also have to cope with a potentially altered facial appearance as a result of treatment (Figure 1a and 1b). Therefore, self-concept may also be threatened resulting in disturbances in body image.

INSERT FIGURE 1A AND 1B ABOUT HERE

There are a limited number of studies relating to appearance change and cancer, with the majority of this research being carried out with breast cancer patients. A small number of studies have been carried out with facial cancer patients. Only two papers were identified that had sought to measure body image as a principal outcome in an eye cancer population. In head and neck cancer, only thirteen studies had aimed to systematically evaluate body image / appearance as a principal outcome and the quality of this research was generally poor. This research treated body image as a simplistic construct and examined it with unsophisticated methods. However, Cash and Pruzinsky (1990), have defined body image as a more complex construct, which encompasses a person's perceptions, thoughts, feelings, and actions.

Reber (1995) defines the 'self' as "one's concept of oneself in as complete and thorough a description as is possible for one to give". Similarly Curbow *et al.* (1990) define the term as "a collection of self-representations". Markus and Wurf (1987) further describe several dimensions that characterise and differentiate self-representations. For example, 'valence' (i.e. positive or negative) and 'time orientation' (i.e. past, present, future). In this way, if a cancer patient has a self-concept that includes a representation of the self on, say a 'physical strength' dimension, this allows this to be further characterised for that person as, for example, 'negative' and 'current'.

It can be seen that both of the above definitions propose that the 'self' is multi-faceted. Rosenberg (1977) proposed that these multiple aspects develop through both internal self-evaluations and interpersonal experiences. Thus, it is suggested that aspects of the self are dynamic, as in response to external events, different aspects of may be changed or modified. It has also been proposed that some self-representations are "core", while others are peripheral (Curbow *et al.*, 1990).

In Higgins' (1987) Self-Discrepancy, two of the components that constitute the self are *ideal* / self and *actual* / self. Ideal / self refers to the aspirations as to who one could potentially be, whereas actual / self refers to conceptions as to who one really is. Higgins (1987) proposes that the greater the magnitude and accessibility of a particular type of self-discrepancy, the more its owner will experience the kind of discomfort associated with it. Individuals are therefore motivated to achieve a match between their ideal / self and actual / self because a discrepancy would result in psychological distress.

Specifically, if a person possesses a discrepancy between ideal / self and actual / self, the current state of his or her attributes does not match the ideal state that he or she hopes or wishes to attain. Higgins (1987) proposes that an ideal / actual self-discrepancy therefore represents the general psychological situation of the absence of positive outcomes (i.e. non-obtainment of one's hopes and desires). This predicts vulnerability to dejection related emotions such as disappointment and dissatisfaction, as in psychological analyses of these emotions they have been described as being associated with discrepancy from hopes, desires or ideal (e.g. Abelson, 1983;Carver and Ganellen, 1983).

A diagnosis of cancer is particularly threatening to the self because it is associated with both fear of pain and death due to the disease, and fears of painful and debilitating and possibly disfiguring treatment. Receiving a diagnosis of cancer is therefore a particularly potent motivation for engaging in adjustments related to the self (Curbow *et al.*, 1990). Self-discrepancy theory proposes, that in response to external threatening events (such as a diagnosis of cancer), aspects of the self are altered in an attempt to maintain an ideal / self - actual / self match, which reduces psychological distress and enhances psychological adjustment.

Cash and Szymanski (1995) highlighted that previous body image research has tended to regard all physical attributes as if they were of equal importance. They proposed that it is the degree to which someone places *importance* on a perceived ideal / actual self-discrepancy that is important, and not merely the discrepancy being present. Thus, an ideal / actual-self discrepancy of major importance (i.e. one that has high *investment*) will have a significant psychological impact, being equivalent to having multiple ideal / actual self-discrepancies that are each associated with lesser degrees of importance. By combining the concept of investment with Higgins' (1987) self-discrepancy theory, they were able to account for the differential degrees of importance that are placed on physical features by different people.

Applying Cash and Szymanski's (1995) work to the cancer field, White (2000) proposed a heuristic cognitive behavioural model of body image and cancer. One component of the model is 'investment in body ideals', which incorporates 'investment', and 'self-discrepancy theory'. Here investment in body ideals is determined by i) the degree to which a person has an investment in the changed body feature or features, and ii) the presence of an ideal / actual self-discrepancy. Therefore, according to the model, cancer patients with high levels of

personal investment in discrete physical attributes should experience more negative psychological consequences following changes in that attribute than patients experiencing similar objective changes, but who have less personal investment in the attribute (see Figure 2). However, this model has not yet been empirically tested and therefore research is needed to evaluate it.

INSERT FIGURE 2 ABOUT HERE

Given that facial appearance has changed, it is likely that ideal / actual self-discrepancies relating to the face exist in people with eye diseases. However, investment in facial appearance is likely to differ between patients with eye cancer and those with other non life threatening eye diseases such as Thyroid Eye Disease (TED). Receiving a diagnosis of cancer may overshadow concerns over appearance when individuals are more concerned with survival than cosmetics (Fallowfield *et al.*, 1987, Pozo *et al.*, 1992). In contrast, survival is unlikely to be the main concern for those individuals with TED. Although TED is associated with exophthlamus (abnormal protrusion or bulging forward of the eye) and in some cases radiotherapy or surgery to the eye socket may be required (Figure 3a and 3b), it is not a life threatening disease.

INSERT FIGURES 3A AND 3B ABOUT HERE

The present study has applied the 'investment in body ideals' component of White's (2000) model to an investigation of the importance of facial appearance in patients with eye cancer. The hypotheses are i) participants with eye cancer and TED will have higher levels of psychological distress compared to control participants, ii) Levels of ideal / actual self-

discrepancies relating to facial appearance will be higher in participants with eye disease (cancer and TED patients) compared to control participants, iii) Facial appearance will be more important to TED patients compared to eye cancer patients, iv) patients with eye cancer will be more concerned about their illness than their facial appearance and patients with TED will be more concerned about their facial appearance than their illness.

2. METHOD

2.1 Experimental Design

A cross-sectional design was used. Eye cancer patients formed the principal patient group. TED patients and non eye disease (Control) participants were comparison groups.

2.2 Participants

Eye cancer (Eye Cancer group), and thyroid eye disease (TED group) outpatients referred to the Tennent Institute of Ophthalmology service based at the Gartnavel General Hospital in Glasgow were recruited for the study. The Eye Cancer group consisted of 44 patients (22 male, 22 female). This represented the natural gender distribution that occurs in this condition, (Harris *et al.*, 1998). The mean age was 62.4 years (SD=13.7). Thirty-eight (86.4%) had a diagnosis of choroidal melanoma, 3 (6.8%) iris melanoma, 1 (2.3%) squamous cell carcinoma, 1 (2.3%) sebaceous gland carcinoma and 1 (2.3%) basal cell carcinoma. Four patients had had enucleations. This distribution was as expected (Kleinstein and Lehman, 1977).

The TED group consisted of 44 patients (8 male, 36 female), i.e. a female to male ratio of 4.5:1. This also represented the natural gender distribution that occurs in this condition, whereby female to male ratios of between 2:1 and 5:1 have been reported (Marcocci *et al.*, 1989; Perros *et al.*, 1993). The mean age was 53.3 years (SD=13.6).

The control participants (Control group) were taken from a 'convenience' sample of the author's family and friends. The Control group consisted of 75 participants (32 male, 43 female) and the mean age was 45.6 years (SD=15.9).

The majority of participants in each group were either married or living with a partner. There were more professionals in the control group compared to the eye disease groups and more people had never worked or were unemployed in the TED group. In addition, more eye cancer patients had retired compared to TED and control participants (see Table 1 for details of these demographics).

INSERT TABLE 1 ABOUT HERE

2.3 Measures of psychosocial functioning

2.3.1 *Brief Symptom Inventory (BSI)* (Derogatis and Melisaraatos, 1983).

This is a familiar 53-item self-report measure of psychological distress. Each item is rated on a 5-point scale of distress from 0 (not at all) to 4 (extremely). The BSI is scored and profiled in terms of nine primary symptom dimensions and three global indices of distress. The Global Severity Index (GSI) was used in the present study. This is the sum of all items divided by the total number of responses (i.e. 53 when there are no missing responses). The GSI is then

converted to standardised score to enable comparison with a relevant reference group. The scale's internal consistency (alpha) ranges from 0.71 to 0.85 and the test-retest reliability (r) ranges from 0.68 to 0.91, indicating acceptable reliability. Convergent validity ranges from 0.92 to 0.98, which is also deemed satisfactory (Croog *et al.*, 1986).

2.3.2 *Hospital Anxiety and Depression Scale (HADS)* (Zigmond and Snaith, 1983).

This is a familiar 14-item self-report measure of anxiety (7 items) and depression (7 items) and is widely used. Each item is scored on a four point scale (0, 1, 2, 3). The range of scores is therefore 0-21 for the anxiety subscale, and 0-21 for the depression subscale. Both the anxiety subscale and the depression subscale were computed in the present study. Internal consistency (alpha) ranges from 0.80 to 0.93 for the anxiety subscale and 0.81 to 0.90 for the depression subscale. Test-retest reliability shows a high correlation of 0.8 (r) of up to two weeks (Herrmann, 1997).

2.4 Body image measures

2.4.1 Appearance Schemas Inventory (ASI) (Cash and Labarge, 1996).

This is a 14-item scale designed to assess core beliefs or assumptions about the importance, meaning, and effects of appearance in one's life. Each item is marked on a five point Likert scale, with responses ranging from: "1 = Strongly Disagree", "2 = Mostly Disagree", "3 = Neither Disagree nor Agree", "4 = Mostly Agree" and "5 = Strongly Agree". The range of mean ASI scores is therefore 1 to 5. The scale's internal consistency (alpha) was 0.84 for college women, indicating good reliability. Convergent and discriminant validity were also deemed satisfactory (Cash and Labarge, 1996). For the present study the authors

recommended that the ASI was administered, in order that further validation data could be gathered (Cash, personal communication).

2.4.2 Appearance Schemas Inventory (Face) – (ASI–face).

This questionnaire is a modified version of the ASI, developed for this study. The authors stated that each applicable item of the ASI could be been re-written to relate specifically to facial appearance (Cash, personal communication). The ASI and ASI-face can each be completed in less than 5 minutes.

2.4.3 Body Image Ideals Questionnaire - (BIQ) (Szymanski and Cash, 1995).

This is an 11-item questionnaire designed to assess perceived discrepancy from and degree of investment in personal ideals on multiple physical attributes. Using a four point Likert scale, the BIQ measures *self-discrepancies*, and *investment* of each attribute. The weighted product of these two measurements can also be calculated. Currently the measure consists of 11 items, with only 2 items relating specifically to the face. This scale's internal consistency (alpha) is 0.82 for college women, indicating good reliability. The authors recommended that the BIQ was administered, in order that further validation data could be gathered (Cash, personal communication).

2.4.4 Body Image Ideals Questionnaire (Face) – (BIQ-face).

This questionnaire is a modified version of Item 4 of the BIQ, developed for this study. The authors stated that Item 4 (ideal facial appearance) could be expanded so that the individual facial features were assessed separately (Cash, personal communication). The BIQ and BIQ-face can each be completed in less than 5 minutes.

2.5 Additional measures

2.5.1 Pictorial Representation of Illness and Self Measure (PRISM) and (PRISM+) (Buchi and Sensky, 1999).

This measure yields a quantitative measure of Self-Illness Separation (SIS), which is the distance between the centres of two disks, one representing 'Self' and one representing 'Illness' with a range of 0-27cm. The SIS reflects a person's perception of the intrusiveness and controllability of their illness or its symptoms in relation to their life as a whole. PRISM+ is an extension of PRISM using any number of further differently coloured disks. In this study two differently coloured disks were used to ascertain the relative importance of 'Facial Appearance' and 'Illness' in Eye Cancer and TED patients' lives. This scale's test-retest reliability (r) is 0.95 and its inter-rater reliability (r) is 0.79 indicating acceptable reliability (Buchi *et al.*, in press).

2.5.2 Clinician-rated facial appearance change scale

This is a single item clinician rated nine point Likert scale developed for this study. It is based on the observer-rated disfigurement scale designed by Katz *et al.* (2000) where the inter-rater reliability (r) was 0.91, indicating acceptable reliability. It measures the degree of facial appearance change from "1" (minimal) to "9" (severe). A clinician who had examined the patient on the day they took part in the present study completed this rating scale for each patient in order to obtain an objective measure of their facial appearance change.

3. RESULTS

3.1 Descriptive statistics

Table 2 presents the means and standard deviations for the scores of the Eye Cancer, TED and Control groups on the HADS (Anxiety subscale), HADS (Depression subscale) and BSI (Global Severity Index subscale, GSI).

INSERT TABLE 2 ABOUT HERE

Table 3 details the means and standard deviations for the Body Image Ideals Questionnaire-face (BIQ-face) and the Appearance Schemas Inventory-face (ASI-face).

INSERT TABLE 3 ABOUT HERE

Table 4 details the means and standard deviations for the mean Discrepancy scores of the Body Image Ideals Questionnaire-face (BIQ-face) for the Eye Disease (Eye Cancer and TED combined) and Control groups.

INSERT TABLE 4 ABOUT HERE

The mean Separation between the 'Self' and 'Facial Appearance' disks on the PRISM was 7.60cm (SD=6.29) for the TED group and 13.9cm (SD=12.13) for the Eye Cancer group. The mean Separation between the 'Self' and 'Illness' disks was 7.42cm (SD=7.71) for the TED

group and 12.13cm (SD=8.27) for the Eye Cancer group. This is shown graphically in Figure 4.

INSERT FIGURE 4 ABOUT HERE

The mean clinician rating of facial appearance change was 1.95 (SD=1.72) for the Eye Cancer group and 4.02 (SD=2.10) for the TED group.

The mean time since diagnosis was 3.3 years (range 0 to 16 years) for the Eye Cancer group and 7.9 years (range 0 to 47 years) for the TED group.

3.2 Analytical statistics

Skewness for data was examined for all variables (whereby significance of skewness = skewness / standard error of skewness). Where necessary (i.e. significance of skewness greater than or equal to 1.96), transformations were carried out by computing the square root of the data (Howitt and Cramer, 2000). The number of participants in the study exceeded that outlined in the proposal (i.e. 26 participants in each group) and can therefore be regarded as having sufficient power.

3.2.1 Age

A one way between subjects analysis of variance (ANOVA) showed an overall significant effect for participant group ($F_{(2,160)}=18.02$, $p<0.01$). Scheffe's range test found that the Eye Cancer group's mean age (62.4, SD=13.7) was significantly higher than that of both the TED group (53.3, SD=13.6), $p<0.05$, and the Control group (45.6, SD=15.9), $p<0.01$. In addition,

the TED group's mean age was significantly higher than that of the Control group, $p<0.05$. A correlation matrix for Age and the variables that were to be analysed between participant groups was calculated to establish where Age was a co-variate. Age was found to significantly co-vary with BIQ-face (discrepancy) ($r = -0.162$, $p<0.05$) and ASI-face ($r = 0.158$, $p<0.05$).

From visual inspection of Table 1, there did not appear to be any further systematic variation in the other demographic variables that might account for any differences between variables.

32.2 Clinician Rating

Significance of the skewness could not be brought to within acceptable limits by transforming the data, hence non-parametric statistics were employed. A Mann-Whitney U test found that the clinician rating for facial appearance change in the TED group was significantly higher than the rating for the Eye Cancer group ($U=382.5$, $N1=44$, $N2=44$, $z=-5.06$, two-tailed $p<0.01$). Thus the TED group's facial appearance was significantly more objectively changed by their illness and /or treatment than the Eye Cancer group.

3.3.3 Time since diagnosis

Significance of the skewness could not be brought to within acceptable limits by transforming the data, hence non-parametric statistics were employed. A Mann-Whitney U test found that the time since diagnosis was not significantly different between the Eye Cancer and TED groups ($U=843.0$, $N1=44$, $N2=44$, $z=-1.044$, two-tailed $p>0.05$).

3.4 Analysis of psychological distress

A one way between subjects analysis of variance (ANOVA) showed an overall significant effect for participant group ($F_{(2,160)}=8.38$, $p<0.01$) on the HADS (Anxiety) subscale. Scheffe's

range test found that the TED group's mean score (8.04, SD=4.62) was significantly higher than that of the Eye Cancer group (5.95, SD=4.19), $p<0.05$ and the Control group (5.08, SD=3.08), $p<0.01$, but no other differences were found. Hence, the TED group were significantly more anxious than both the Eye Cancer and Control groups.

A one way between subjects analysis of variance (ANOVA) showed an overall significant effect for participant group ($F_{(2,160)}=17.21$, $p<0.01$) on the HADS (Depression) subscale. Scheffe's range test found that the TED group's mean score (5.68, SD=4.08) was significantly higher than that of the Eye Cancer group (3.39, SD=3.04), $p<0.05$ and the Control group (2.12, SD=2.21), $p<0.01$. The Eye Cancer group's mean score was also significantly higher than that of the Control group, $p<0.05$. Hence, the TED group were significantly more depressed than both the Eye Cancer and Control groups and the Eye Cancer group were significantly more depressed than controls.

A one way between subjects analysis of variance (ANOVA) showed an overall significant effect for participant group ($F_{(2,160)}=5.59$, $p<0.01$) on the Brief Symptom Inventory (Global Severity Index). Scheffe's range test found that the TED group's mean score (58.5, SD=12.93) was significantly higher than that of the Control group (51.15, SD=11.56), $p<0.01$ but no other differences were found. Hence, the TED group were overall significantly more distressed than the Control group and there were no differences between the Eye Cancer group and the other groups.

3.2.5 The Body Image Ideals Questionnaire (BIQ) and Appearance Schemas Inventory (ASI)

These measures were administered for purposes of gathering further data for validation only. The data will be reported elsewhere (see Appendix 4.2 for means and standard deviations for these two measures).

3.2.6 Body Image Ideals Questionnaire-face (BIQ-face)

An extracted question from BIQ-face is provided here to assist in interpretation:

> **1a) My ideal facial features (eyes) are:**
>
> (response in the range "0 = Exactly as I am", "1 = Almost as I am", "2 = Fairly unlike me" or "3 = Very unlike me").
>
> **1b) How important to you are your ideal facial features (eyes)?**
>
> (response in the range "0 = Not important", "1 = Somewhat important", "2 = Moderately important" or "3 = Very important").

In this sample, the internal consistency (alpha) for part a) of the BIQ-face was 0.64 indicating moderate reliability and 0.83 for part b) indicating good reliability.

The following three scores can be derived from the BIQ-face:

1. Part a) Mean discrepancy score: (note: 0 scores are first converted to –1):

Range -1 to +3 (whereby -1 relates to "my ideal is exactly as I am", and, +3 relates to "my ideal is very unlike me").

2. Part b) Mean importance score:

Range 0 to +3 (whereby 0 relates to "my ideal is not important", and, +3 relates to "my ideal is very important").

3. Part a multiplied by Part b) Mean weighted score:

Range –3 to +9 (whereby -3 relates to "my ideal is exactly as I am and is very important", signifying a very important *congruence*, and, +9 relates to "my ideal is very unlike me and is very important", signifying a very important *discrepancy).*

An analysis of covariance (ANCOVA) was applied to the two groups (Eye Disease and Controls) in order to see whether there was a difference in BIQ-face mean discrepancy (i.e. mean of part a), controlling for age. The main effect of having eye disease or not was not significant ($F_{(1,160)}$=1.36, p>0.05). The adjusted means are shown in Table 5. Thus there was no difference in the level of ideal-actual self discrepancy in relation to the face in eye disease patients and non eye disease controls.

INSERT TABLE 5 ABOUT HERE

An independent samples t-test found that the mean BIQ-face importance score (i.e. mean of part b) for the TED group (1.57, SD=0.84) was not significantly higher (t=-1.789, df=86, two-tailed p>0.05) than that of the Eye Cancer group (1.21, SD=0.99). Thus, TED and Eye Cancer groups both reported their mean facial 'ideal' as being between "somewhat important" and "moderately important".

An independent samples t-test found that the mean BIQ-face weighted score (i.e. mean of part a multiplied by part b) of the TED group (1.61, SD=1.94) was significantly higher (t=-3.42, df=86, two-tailed $p<0.01$) than that of the Eye Cancer group (0.32, SD=1.57). Thus, the TED group had significantly less congruence between ideal-actual self discrepancy presence in facial appearance and its importance than the Eye Cancer group.

3.2.7 Appearance Schemas Inventory-face (ASI-face)

In this sample, the internal consistency (alpha) for the ASI-face was 0.85 indicating good reliability.

An analysis of covariance (ANCOVA) was applied to the two groups (Eye Cancer and TED) in order to see whether there was a difference in ASI-face mean, controlling for age. The main effect of participant group was significant ($F_{(1,85)}=6.85$, $p<0.01$). Thus the TED group were significantly more facial appearance schematic than the Eye Cancer group. The adjusted means are shown in Table 6.

INSERT TABLE 6 ABOUT HERE

3.2.8 PRISM

Significance of the skewness could not be brought to within acceptable limits by transforming the data, hence non-parametric statistics were employed.

i) Relative importance of Illness and Facial Appearance within groups (see also Figure 4).

The difference between Self-Facial Appearance separation and Self-Illness separation was not significant in the Eye Cancer group (Wilcoxon, N=44, z=-0.860, two-tailed $p>0.05$). The difference between Self-Facial Appearance separation and Self-Illness separation was not significant in the TED group (Wilcoxon, N=44, z=-0.159, two-tailed $p>0.05$). Thus the Eye Cancer group assigned their illness and their facial appearance as being equally important in their lives. The TED group also assigned their illness and their facial appearance as being equally important in their lives.

ii) Relative Importance of Illness and Facial appearance between groups (see also Figure 4).

A Mann-Whitney U test found that the Self-Facial Appearance separation was significantly longer for the Eye Cancer group than for the TED group (U=576.5, N1=44, N2=44, z=-3.28, two-tailed $p<0.01$). A second Mann-Whitney U test found that the Self-Illness separation was significantly longer for the Eye Cancer group than for the TED group (U=668.5, N1=44, N2=44, z=-2.51, two-tailed $p<0.05$). Thus, the TED group assigned both illness and facial appearance as being significantly more important in their life compared to the Eye Cancer group.

4. DISCUSSION

TED patients were significantly more anxious, depressed and overall more psychologically distressed than the participants in the Eye Cancer and Control groups. However, psychological distress has been reported as a feature of hyperthyroidism (Iacovides *et al.*, 2000; Joffe and Marriott, 2000). As hyperthyroidism is present in the majority of patients diagnosed with

TED, this thyroid imbalance may have therefore pre-disposed some TED patients to psychological distress, accounting for the higher levels of distress seen in this group.

Although the Eye Cancer group were more depressed than Controls (on HADS depression subscale), the mean score was below that deemed to be clinically significant (Zigmond and Snaith, 1983). They were also not different to controls on the HADS anxiety subscale or in terms of global psychological distress (BSI, GSI). This finding is inconsistent with rates of distress in cancer patients reported in the research literature (Derogatis *et al.* 1983; Zabora *et al.* 2001). However, high psychological distress has been found to be more common in cancer diagnoses associated with a poorer prognosis coupled with feelings of responsibility, such as lung cancer (Zabora *et al.*, 2001). Lung cancer has a poorer prognosis than eye cancer and is therefore likely to have a more adverse effect on the patient's life on a day to day basis. In addition, lung cancer patients may feel responsible for their diagnosis through lifestyle behaviours whereas eye cancer patients would be unlikely to. Self attribution may therefore play a critical role in the actual levels of distress of cancer patients (Faller *et al.*, 1995; Faller *et al.*, 1996).

It was hypothesised that, as eye cancer patients have to cope with a life threatening diagnosis, this may overshadow their concerns over their facial appearance when they are more concerned with survival. However, on the PRISM they rated their illness and facial appearance as being equally as important to them in their lives as a whole. Survival was felt to be an important factor in terms of how eye cancer patients would view their illness compared to their facial appearance. However, 'survival' was not actually assessed. Perhaps the concept of 'Illness' was too global for patients to access the cancer specific issue of survival when completing this measure. Therefore, survival is clearly only a part of what constitutes 'Illness'

to eye cancer patients. The TED group also rated illness and facial appearance as being equally important in their lives on the PRISM, when it was expected that they might view their facial appearance as more important. However, they placed both 'facial appearance' and 'illness' disks closer to the 'self' disk than eye cancer patients. Thus, the expectations of the outcome of PRISM based on assumptions about disease involving generic aspects of illness (i.e. that having cancer is "worse" than having TED), were incorrect. The PRISM showed that the burden of suffering due to having TED was significantly higher than it was due to having eye cancer, in this sample.

The 'investment in body ideals' component of White's (2000) model is essentially a combination of Higgins (1987) self-discrepancy theory and Cash and Szymanski's (1995) theory of investment. Given that facial appearance had changed, it was felt that people with eye disease may have higher ideal / actual self-discrepancies in relation to facial appearance compared to controls. This was not supported in this sample. Small ideal / actual self-discrepancies in relation to facial appearance were present in each of the three groups (Eye Cancer, TED and Control) and there were no significant differences. However, according to Higgins (1987), individuals are motivated to achieve a match between their ideal and actual selves in order to facilitate psychological functioning, so it is possible that this is what occurred in the present study. The eye cancer group were objectively rated as having only minimally visible changes. Therefore, it is possible that, as a result of this 'floor effect' of the objective rating, the eye cancer patients in this sample were not qualitatively different to controls in terms of their facial appearance. Thus this low objective rating may have also accurately reflected the way the eye cancer patients viewed their facial appearance. However, as a rating of facial appearance change from the patient's point of view was not taken, this has to remain as speculation. As the TED group's facial appearance was rated as being

significantly more objectively changed than the Eye Cancer group, it might have been expected that the TED group would have higher discrepancies between ideal / self and actual / self than eye cancer or control participants in relation to the face. However, this was not found either, again suggesting that perhaps individuals had reduced the discrepancy between their ideal and actual selves. Heidrich (1999) reported increasing age related to more congruence between ideal / self and actual / self (i.e. less discrepancy). In the present study, it is therefore possible that the congruence between ideal / self and actual / self seen in the TED group was due in part to increasing age (the mean age of this group was 53.3.years).

According to White's (2000) model, the presence of a discrepancy (regardless of size) is not sufficient in itself to produce negative body image emotions such as anxiety and depression. The discrepancy has to relate to a high level of investment for negative emotions to be experienced. The hypothesis that TED patients would have higher investment in facial appearance compared to eye cancer patients was supported by outcomes from the ASI-face and the BIQ-face weighted score. Although TED and Eye Cancer groups both reported their mean facial 'ideal' as being between "somewhat important" and "moderately important", the TED group had significantly less *congruence* between ideal / actual self-discrepancy presence in facial appearance and its importance as measured by the BIQ-face weighted score. In other words, although the discrepancy was small in both groups and the importance score was not significantly different between the groups, taken together (the weighted effect) the TED group were more concerned about their current ideal / actual self-discrepancy with respect to facial appearance than the Eye Cancer group.

Therefore, the TED group did have higher investment in their facial appearance than the eye cancer group, which was predicted. However, it cannot be stated that this was due to a lesser

concern regarding their illness, which was the reason for arriving at this hypothesis. They viewed their illness and facial appearance as equally important on the PRISM and therefore the relationship between illness and appearance is more complex than originally thought.

The TED group also endorsed the ASI-face significantly higher than the Eye Cancer group, which showed that they had more affect laden cognitive constructs with respect to facial appearance. This means they would be more likely to be affected by body image experiences regarding their facial appearance, than eye cancer patients. The TED group's ASI-face mean score was also higher than that obtained by a normative clinical sample identified to have 'extreme body image disturbance' on the ASI (Cash and Labarge, 1996). The strongest correlate when developing the ASI was body image affect suggesting that body-image dysphoria is increased by appearance-schematicity. In the present study, neither BIQ-face (weighted) nor ASI-face were significantly correlated with any measures of distress. However, this may be because this was a measure of global distress and not distress specific to body image. Hence the link between the 'investment in body ideals' component of the model and resultant psychological distress remains unclear. This link between components of the model was not specifically being addressed in this study. However, the findings discussed above have provided evidence for the validity of the 'investment in body ideals' component of White's (2000) model.

Limitations of the research

There was a wide range in time since diagnosis within both groups. By referring to Figures 1a and 1b it can be seen that this is the same patient, but presenting at different times to the clinic. This is a typical example of eye disease presentation, whereby a higher rate of facial appearance change due to the illness may be apparent in the early stages and, following

treatment will be much less apparent (Moshfeghi, *et al.*, 2000). Consequently, in the present study there was a wider range in objective facial appearance change than would have been expected if they had been matched in terms of the time since diagnosis. This may also have been a confounding factor, as the issues relating to the experience of eye disease are likely to have been different for patients at different stages in the progression of their illness and its treatment.

No ratings were collected of appearance change as a result of the eye disease from the patient's point of view. This would have provided a useful comparison in terms of how it compared to clinician rating. It would have also helped to establish if there was any relationship between ideal / actual self-discrepancy with respect to facial appearance and patient rated appearance change. This would have provided an insight into whether or not ideal / actual self-discrepancies were being subjectively reduced by patients.

PRISM was designed for use in patients with physical health problems, hence it was felt that its use in an eye disease population study was appropriate. However, it would have been useful in this study to record qualitative data relating to individual meanings as to why patients placed the disks where they did on the board and this was not done. If this procedure had been carried out, it would have provided greater insight into the associations made between distances placed between Self and Illness and Self and Facial Appearance by patients. In particular it would have provided information as to whether or not individuals were thinking of survival.

The authors of PRISM have acknowledged that, as a measure in its infancy, there are currently some limitations in terms of how meaningful the 'self-illness separation (SIS)' outcome is

(Buchi et al. in press). For example, they have established from qualitative interviews with patients that low SIS is associated with high intrusiveness of illness and loss of autonomy. However, they state that it remains unclear whether doubling the SIS represents twice as much suffering and how this should be interpreted. They postulate that SIS may well be best interpreted in terms of several ranges of values, but that this requires further evaluation. In addition, there is no clear definition of the 'self' provided for patients, although patients do not appear to have difficulty in ascertaining what this is and what is required of them in terms of completion of the measure.

The limitations of the BIQ and ASI are that those studies that have ascertained their validity and reliability to date have used primarily female college students. Thus the generalisability of usefulness of the measures in an illness population must be made with caution. The present study has gathered further data for validation of these measures in a mixed gender, illness population which will be reported elsewhere. It is hoped that this will provide some evidence for the appropriateness of their use in this population in addition to that of college females. The reliability of the modified versions (ASI-face and BIQ-face) ranged from acceptable to good in the present study, hence these measures were deemed to be appropriate.

Conclusions and suggestions for future research

Further work is needed with respect to the application of 'self-discrepancy theory' and 'investment in body ideals' in cancer patients. In the present study, patients did not have higher ideal / actual self-discrepancies relating to facial appearance than people without eye disease and in all groups the level of discrepancy was small. It is therefore recommended that the model is evaluated with a group of cancer patients who have more observable appearance changes in order to gain a better understanding of the mechanisms involved in determining

ideal / actual self-discrepancies. It would also be useful to carry out further research investigating how self-discrepancy ratings vary with participant age.

In future research, it is also recommended that both time since diagnosis and objective rating of appearance change be matched and that a subjective rating of appearance change be taken. It would also be helpful to establish longitudinal aspects of self-discrepancies. Currently White's (2000) model does not take these aspects into account. For example, it may be that ideal / actual self-discrepancies are higher at the time of diagnosis but then fall with time as appearance returns to 'normal'. However, at the present time this is unclear. If this was found to be the case, the model could be modified accordingly. Finally, although this model was developed for cancer and not as a model to be applied to other diseases, based on the data in this study it could feasibly be applied to other illnesses in which there have been appearance changes.

References

Abelson RP. 1983. Whatever became of consistency theory? *Personality and Social Psychology Bulletin*, **9:** 37-54.

American Psychiatric Association 1980. *Diagnostic and Statistical Manual of Mental Disorders (3rd Edition)*. Washington, DC: American Psychiatric Association.

Brandberg Y, Kock E, Oskar K, Trampe EA, Seregard S. 2000. Psychological reactions and quality of life in patients with posterior uveal melanoma treated with ruthenium plaque therapy or enucleation: a one year follow-up study. *Eye,* **14:** 839-846.

Brennan J. 2001. Adjustment to cancer – coping or personal transition? *Psycho-Oncology* **10**: 1-18.

Buchi S, Sensky T. 1999. PRISM: Pictorial Representation of Illness and Self Measure. *Psychosomatics,* **40**: 314-20.

Buchi S, Buddeberg C, Kaghofer R, Russi EW, Brandli O, Schlosser C, Stoll T, Villiger PM, Sensky T. (in press). Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure) - a brief method to assess suffering.

Carver CS, Ganellen RJ. 1983. Depression and components of self-punitiveness: High standards, self-criticism and overgeneralisation. *Journal of abnormal psychology*, **92**: 330-337.

Cash TF, Labarge AS. 1996. Development of the Appearance Schemas Inventory: A New Cognitive Body-Image Assessment. *Cognitive Therapy and Research*, **20**(1): 37-50.

Cash TF, Pruzinsky T. 1990. Integrative themes in body image development, deviance and change. In *Body images: Development, deviance, and change*. (T.F. Cash and T Pruzinsky Eds.). Guilford Press, New York.

Cash TF, Szymanski ML. 1995. The development and validation of the Body Image Ideals Questionnaire. *Journal of Personality Assessment* **64**(3): 466-477.

Cash TF. 2001. Personal communication.

Croog SH, Levine S, Testa MA. 1986. The effects of anti-hypertensive therapy on quality of life. New England Journal of Medicine, **314**(26): 1657-1664.

Cruickshanks KJ, Fryback DG, Nondahl DM, Robinson NAB, Keesey U, Dalton DS, Robertson DM, Chandra SR, Mieler WF, Zakov ZN, Custer PL, Del Priore LV, Albert DM. 1999. Treatment choice and quality of life in patients with choroidal melanoma. *Archives of Ophthalmology,* **117:** 461-467.

Curbow B, Somerfield M, Legro M, Sonnega J. 1990. Self-concept and cancer in adults: Theoretical and methodological issues. *Social Science and Medicine* **31**: 115-28.

Derogatis LR, Melisaraatos N. 1983. The Brief Symptom Inventory (BSI): An introductory report. *Psychol Med* **13**: 595-606.

Derogatis LR, Morrow GR, Fetting JH, Penman D, Piasetsky S, Schmale AM, Henrichs M, Carnicke CLM. 1983. The prevalence of psychiatric disorders among cancer patients. *J Am. Med. Assoc.* **249**: 751-757.

ESRC Review of Government Classifications. 1998. London: Office for National Statistics.

Faller H, Schilling S, Lang H. 1995. Causal attribution and adaptation among lung cancer patients. *J Psychosom Res* **39**: 619-627.

Faller H, Lang H, Schilling S. 1996. Causal 'cancer personality' attribution: An expression of nonadaptive coping with illness. *Z Klin Psychol Psychiatr Psychother* **44**: 104-116.

Fallowfield LJ, Baum M, Maguire GP. 1987. Addressing the psychological needs of the conservatively treated breast cancer patient: Discussion paper. *Journal of the Royal Society of Medicine*, **80:** 696-700.

Harris V, Sandridge AL, Black RJ, Brewster DH, Gould A. 1998. *Cancer registration statistics Scotland 1986-1995*. Edinburgh: ISD Scotland Publications.

Heidrich SM. 1999. Self-discrepancy across the life span. *Journal of Adult Development*, **6**(2): 119-130.

Herrmann C. 1997. International experiences with the hospital anxiety and depression scale - a review of validation data and clinical results. *Journal of Psychosomatic Research*, **42**(1): 17-41.

Higgins ET. 1987. Self-Discrepancy: A theory relating self and affect. *Psychological review*, **94**(3): 319-340.

Howell DC. 1997. *Statistical Methods for Psychology, 4th Ed.* London: International Thomson Publishing.

Howitt D, Cramer D. 2000. *An introduction to statistics in Psychology (2nd Edition).* London: Prentice Hall.

Iacovides A, Fountoulakis KN, Grammaticos P, Ierodiakonou C. 2000. Difference in symptom profile between generalised anxiety disorder and anxiety secondary to hyperthyroidism. *International Journal of Psychiatry in Medicine*, **30**(1): 71-81.

Joffe RT, Marriott M. 2000. Thyroid hormone levels and recurrence of major depression. *American Journal of Psychiatry*, **157**(10): 1689-1691.

Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. 2000. Reliability and Validity of an Observer-Rated Disfigurement Scale for Head and neck cancer patients. *Head and Neck*, **22**: 132-141.

Kleinstein RN, Lehman HF. 1977. *American Journal of Ophthalmic Physiology*, **54**(1): 49-51.

Marcocci C, Bartalena L, Bogazzi F. 1989. Studies on the occurrence of ophthalmopathy in Graves' disease. *Acta Endocrinologica*, **120**(4): 473-478.

Markus H, Wurf E. 1987. The dynamic self-concept: a social psychological perspective. *A. Rev. Psychol.* **38**: 299-337.

Moshfeghi DM, Moshfeghi AA, Finger PT. 2000. Enucleation. *Survey of ophthalmology*, **44**(4): 277-301.

Perros P, Crombie AL, Matthews JN. 1993. Age and gender influence the severity of thyroid-associated ophthalmopathy: a study of 101 patients attending a combined thyroid-eye clinic. *Clinical Endocrinology*, **38**(4): 367-372.

Pozo C, Carver CS, Noriega V. 1992. Effects of mastectomy versus lumpectomy on emotional adjustment to breast cancer: A prospective study of the first year post surgery. *Journal of Clinical Oncology,* **10**: 1292-1298.

Reber AS. 1995. *Dictionary of psychology (2nd Edition).* London: Penguin.

Rosenberg M. 1977. *Conceiving the self.* New York: Basic Books.

Seddon JM, Gragoudas ES, Albert DM. 1985. Comparison of survival rates for patients with uveal melanoma after treatment with proton beam irradiation. *American Journal of Ophthalmology*, **99:** 282-290.

Sisley K. 1999. Posterior Uveal Melanoma. *Atlas of Genetics and Cytogenetics in Oncology and Haematology.*

Szymanski ML, Cash TF. 1995. Body image disturbances and self-discrepancy theory: expansion of the Body Image Ideals Questionnaire. *J. Soc. Clin. Psychology.* **14**(2): 134-146.

White CA. 2000. Body image dimensions and cancer: A heuristic cognitive behavioural model. *Psycho Oncology,* **9:** 183-192.

Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. 2001. The prevalence of psychological distress by cancer site. *Psycho-oncology*, **10:** 19-28.

Zigmond AS, Snaith RP. 1983. The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, **67**: 361-370.

LIST OF TABLES AND FIGURES

List of Tables

		Pages
Table 1.	Demographics for the participant sample.	124
Table 2.	Means and standard deviations for measures of psychological distress (HADS and BSI).	125
Table 3.	Means and standard deviations for the Appearance Schemas Inventory-face (ASI-face) and Body Image Ideals Questionnaire-face (BIQ-face).	126
Table 4.	Means and standard deviations for the Mean Discrepancy scores of Body Image Ideals Questionnaire-face (BIQ-face) for Eye disease and Controls.	127
Table 5.	Unadjusted and Adjusted means for BIQ-face (discrepancy).	128
Table 6.	Unadjusted and Adjusted means for ASI-face.	129

List of Figures

		Pages
Figure 1a. and 1b.	Photograph of an Eye Cancer patient before and following enucleation.	130
Figure 2.	A Heuristic Cognitive Behavioural model of cancer (White 2000).	131
Figure 3a. and 3b.	Photograph of Thyroid Eye Disease patient before and following surgery.	132
Figure 4.	Plot of mean PRISM: Self- Facial Appearance and Self-Illness Separations.	133

Table 1. Demographics for the participant sample (n=163).

		Participant Group					
		Eye Cancer		TED		Control	
		N	%	N	%	N	%
Marital Status:							
Single		**2**	4.5	**3**	6.8	**16**	21.3
Married / living with partner		**33**	75	**27**	61.4	**51**	68
Divorced / Separated		**2**	4.5	**7**	15.9	**5**	6.7
Widow / Widower		**7**	15.9	**7**	15.9	**3**	4
New SEC[1]							
L1	Employers (large)	**0**	0	**0**	0	**0**	0
L2	Managers (large)	**0**	0	**0**	0	**0**	0
L3	Professionals	**9**	20.4	**6**	13.7	**30**	40
L4	Associate professionals	**8**	18.2	**2**	4.5	**13**	17.3
L5	Managers (small)	**3**	6.8	**2**	4.5	**2**	2.7
L6	Higher supervisors	**0**	0	**1**	2.3	**1**	1.3
L7	Intermediate occupations	**7**	15.9	**8**	18.2	**12**	16
L8	Employers (small)	**1**	2.3	**0**	0	**0**	0
L9	Own account	**0**	0	**0**	0	**2**	2.7
L10	Lower supervisors	**1**	2.3	**0**	0	**2**	2.7
L11	Craft and related occupations	**1**	2.3	**2**	4.5	**1**	1.3
L12	Semi-routine occupations	**7**	15.9	**8**	18.2	**4**	5.3
L13	Routine occupations	**4**	9.1	**6**	13.6	**4**	5.3
L14	Never worked / long term unemployed	**0**	0	**8**	18.2	**1**	1.3
L15	Full time student	**1**	2.3	**1**	2.3	**1**	1.3
L16	Not stated or inadequately described	**2**	4.5	**0**	0	**2**	2.7
Retired:							
Yes		**22**	50	**11**	25	**8**	10.7
No		**22**	50	**33**	75	**67**	89.3

[1] Social Economic Classification (ESRC Review of Government Classifications, 1998)

Table 2 Means and standard deviations for measures of psychological distress for the participant sample (n=163).

Group	HADS (Anxiety) Score	HADS (Depression) Score	BSI (Global Severity Index)
Eye Cancer N=44	**5.95** (*4.19*)	**3.39** (*3.04*)	**52.79** (*10.69*)
TED N=44	**8.04** (*4.62*)	**5.68** (*4.08*)	**58.5** (*12.93*)
Control N=75	**5.08** (*3.08*)	**2.12** (*2.21*)	**51.15** (*11.56*)

Means are shown in **bold** and Standard Deviations are shown in brackets in *italics*.

Table 3. Means and standard deviations for the Body Image Ideals Questionnaire-face (BIQ-face) and Appearance Schemas Inventory-face (ASI-face).

Measure	Eye Cancer N=44	TED N=44	Control N=75
BIQ-face (part a) (Discrepancy)	**0.09** *(0.93)*	**0.48** *(0.78)*	**0.25** *(0.88)*
BIQ-face (part b) (Importance)	**1.21** *(0.99)*	**1.57** *(0.84)*	**1.19** *(0.83)*
BIQ-face (a x b) (Weighted)	**0.32** *(1.58)*	**1.61** *(1.94)*	**0.39** *(1.49)*
ASI-face	**2.57** *(0.83)*	**3.02** *(0.65)*	**2.30** *(0.52)*

Means are shown in **bold** and Standard Deviations are shown in brackets in *italics*.

Table 4. -Means and standard deviations for the Mean Discrepancy scores of Body Image Ideals Questionnaire-face (BIQ-face) for eye disease and control groups.

BIQ-face	Eye Disease Group N=88	Control N=75
Mean discrepancy	**0.29** (0.87)	**0.25** (0.88)

Means are shown in **bold** and Standard Deviations are shown in brackets in *italics*.

Table 5. Unadjusted and Adjusted means for BIQ-face mean discrepancy score for Eye Disease Group and Control group.

BIQ-face mean discrepancy score	Eye Disease Group N=88	Control N=75
Unadjusted	0.29	0.25
Adjusted	0.35	0.18

Table 6. Unadjusted and Adjusted means for ASI-face.

Mean	Eye Cancer N=44	TED N=44
Unadjusted	2.57	3.02
Adjusted	2.57	3.01

Figure 1a. Photograph of an Eye Cancer patient before enucleation

Figure 1b. Photograph of an Eye Cancer patient after enucleation with prosthetic orbital implant.

Note: Patient consent for the use of these photographs has been given.

Figure 2 – A Heuristic Cognitive Behavioural model of cancer (White 2000).

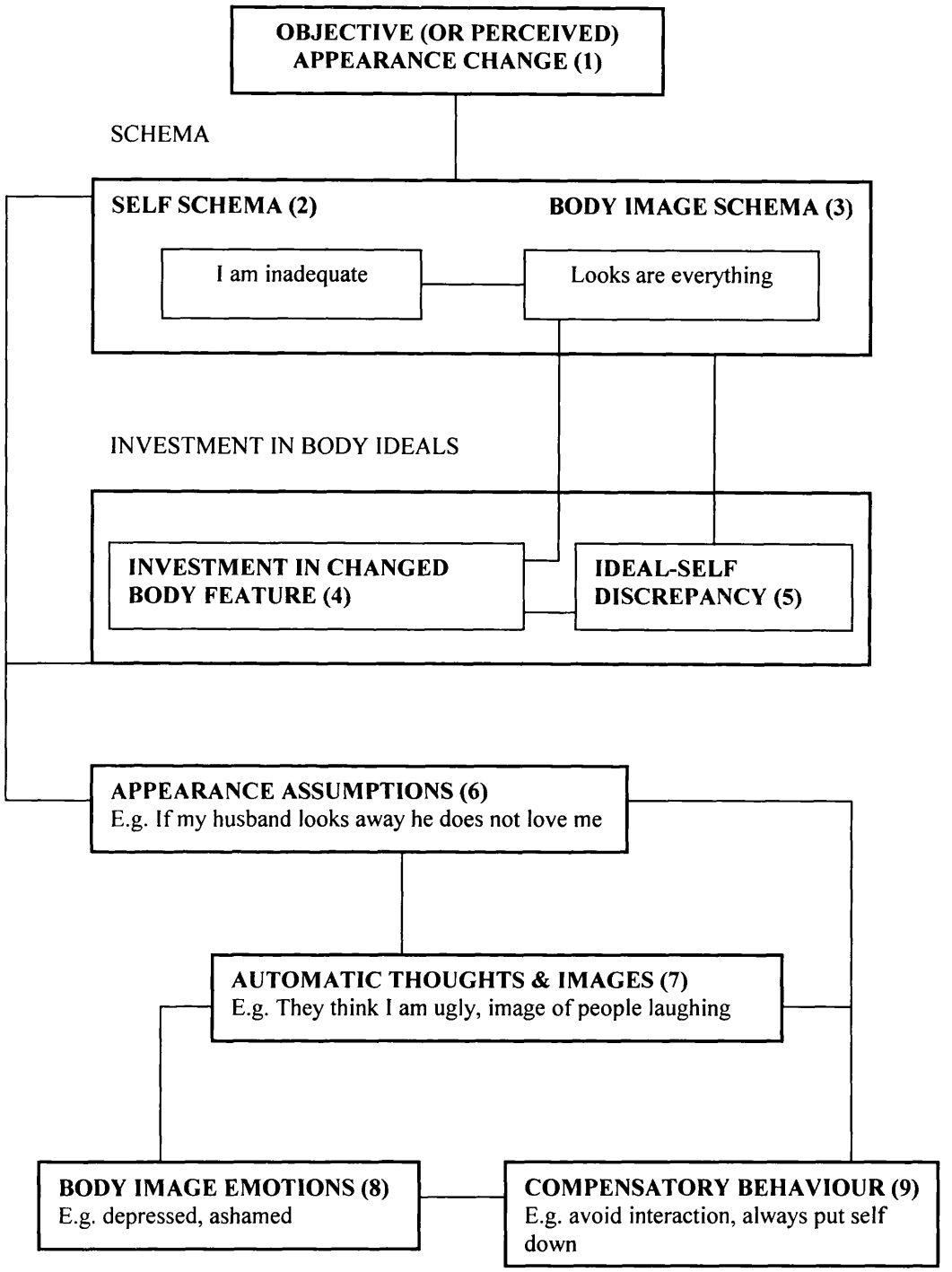
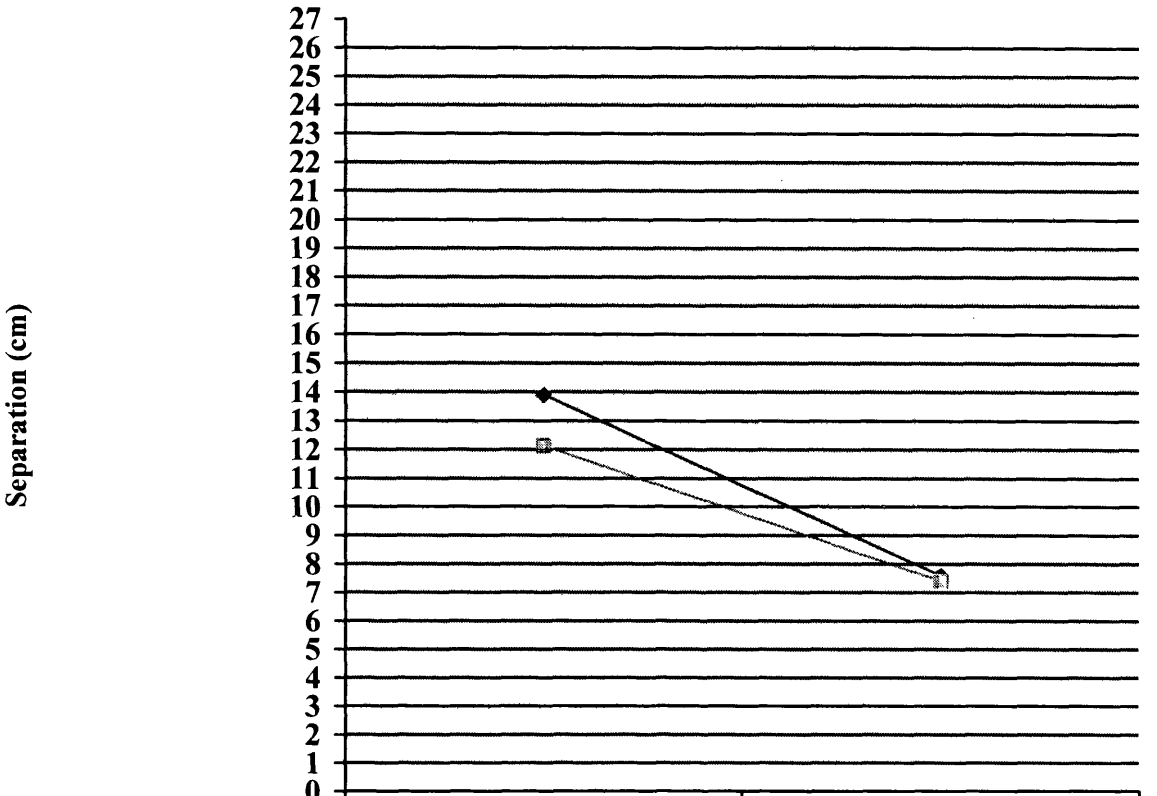


Figure 3a. Photograph of a Thyroid Eye Disease patient before surgery.

Figure 3b. Photograph of Thyroid Eye Disease patient after surgery.

Note: Patient consent for the use of these photographs has been given.

Figure 4. – Plot of mean PRISM Self-Facial Appearance and Self-Illness separations



	Eye cancer	TED
Mean Self-Facial Appearance Separation	13.9	7.6
Mean Self-Illness Separation	12.13	7.41

5. SINGLE CASE RESEARCH STUDY - ABSTRACT

Targeting Self-esteem in the Treatment of Social Anxiety: A Single Case Experimental Design.

Prepared for submission to *Behavioural and Cognitive Psychotherapy*

(See Appendix 5.1 for notes to contributors).

Targeting Self-esteem in the Treatment of Social Anxiety: A Single Case Experimental Design.

Nicola J. Brown
Department of Psychological Medicine
University of Glasgow
Glasgow
G12 0XH

Abstract

Brewin (1996) has postulated that the mental representations thought to underlie social phobia are more global and more often concern the self than those thought to underlie more circumscribed disorders, such as specific phobias. Low self-esteem is thus implicated in the origin and maintenance of social phobia. Fennell (1997) has proposed the first cognitive conceptualisation of low self-esteem, along with an integrated treatment programme derived from the model. She emphasises that the effectiveness of schema-focused cognitive therapy remains as yet largely untested.

This single case research study involved N, a patient with social phobia. The aim was to test Fennell's (1997) assertion that previous interventions should have some impact on the patient's belief system by the time attention in therapy is directed towards the core belief. N's core belief was "I am inadequate". The research design was an extension of an A–B-C design (Kazdin, 1982). An additional aim was to establish if there was any differential impact of interventions on social anxiety.

Behavioural interventions significantly reduced social anxiety, but not strength of belief in core belief. The core belief had to be directly challenged in order for a statistically significant decrease in strength to be obtained. The results suggest that without cognitive interventions, an underlying cognitive vulnerability remains, predisposing the patient to future relapse. This single case research provides evidence for the importance of cognitive interventions directly targeting core belief associated with low self-esteem, in the treatment of patients with social phobia.

Key words:
Social phobia, social anxiety, self-esteem, cognitive behaviour therapy, single n.

APPENDIX 1

Small Scale Service Evaluation Project

		Pages
1.1	Copy of Notes for Contributors to *Health Bulletin.*	**138**

Notes for Contributors

Papers, articles and other contributions should be sent to the Editor, Health Bulletin, Scottish Executive Health department, Room IE05, St Andrew's House, Edinburgh EH1 3DE. They must be submitted exclusively for Health Bulletin. Acceptance is on the understanding that editorial revision may be necessary. All papers are reviewed by the Editor and by peer review, referees being drawn from a panel of appropriate professionals. No correspondence can be entered into in relation to articles found to be unsuitable and returned to authors.

Potential contributions can be submitted in two ways. Material submitted for publication must be typewritten on one side of the paper only, in double spacing and with adequate margins, and each page should be numbered. The top typed copy should be submitted, with four other copies. We are willing to receive one copy typewritten in the above format and accompanied by a disk (Microsoft Word version 98, Excel for tables and figures). All papers should be prefaced by a structured Abstract, of about 250 words in length. It should normally contain six clearly headed sections entitled Objective, Design, Setting, Subjects, Results and Conclusion. The name, appointment and place of work of the authors should be supplied on a separate title page. This same page should include the full postal address of one author, to whom correspondence and reprints will be directed. There should be adequate references to any relevant previous work on the subject; these references should appear at the end of the material on a separate page or pages, using the Vancouver style, which in the case of papers in journals includes:

Surname and initials of author(s)
Title of paper
Full name of journal
Year published
Volume number
Opening and closing page numbers

Reference to books should similarly include author's name and initials, full title, edition (if necessary), place of publication, publisher's name, year and, if required, volume number, chapter number or page number.

Short Communications. *Health Bulletin* publishes short communications (not exceeding four pages in length) as a separate section, and we aim to offer speedier publication for these. Material intended for this section should be submitted in the above form, and the covering letter should state the intention.

Proofs

Contributors will receive one set of proofs. This should be read carefully for printer's errors, and any tables, figures and legends should be checked. Alterations should be kept to a minimum, and the proofs should be returned promptly.

Reprints

Ten reprints will be supplied free of charge.

APPENDIX 2

Major Research Project Literature Review

		Pages
2.1	Copy of Information for Contributors to *Psycho-Oncology.*	**140-141**
2.2	Observer-rated disfigurement scale.	**142**

Instructions to Authors

Initial Manuscript Submission. Authors in North America should submit four copies of the manuscript (including copies of tables and illustrations) to Dr Jimmie C. Holland, Memorial Sloan-Kettering Cancer Center, 1275 York Avenue, New York 10021, USA. All other manuscripts should be submitted to Dr Maggie Watson, Department of Psychological Medicine, The Royal Marsden Hospital, Downs Road, Sutton, Surrey, SM2 5PT, UK.

Authors **must** also supply:

- an electronic copy of the final version (see section below),
- a Copyright Transfer Agreement with original signature(s) - without this we are unable to accept the submission, and
- permission grants - if the manuscript contains extracts, including illustrations, from other copyright works (including material from on-line or intranet sources) it is the author's responsibility to obtain written permission from the owners of the publishing rights to reproduce such extracts using the Wiley Permission Request Form. Permission grants should be submitted with the manuscript.

Submitted manuscripts should not have been previously published and should not be submitted for publication elsewhere while they are under consideration by Wiley. Submitted material will not be returned to the author unless specifically requested.

Electronic submission. The electronic copy of the final, revised manuscript must be sent to the Editor **together with** the paper copy. Disks should be PC or Mac formatted; write on the disk the software package used, the name of the author and the name of the journal. We are able to use most word processing packages, but prefer Word or WordPerfect

Illustrations must be submitted in electronic format where possible. Save each figure as a separate file, in **TIFF** or **EPS** format preferably, and include the source file. Write on the disk the software package used to create them; we favour dedicated illustration packages over tools such as Excel or Powerpoint.

Manuscript Style. The language of the journal is English. All submissions including book reviews must have a title, be printed on one side of the paper, be double-line spaced and have a margin of 3cm all round. Illustrations and tables must be printed on separate sheets, and not be incorporated into the text.

- The **title page** must list the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)**.

Supply a summary of up to 200 words for all articles [except book reviews]. A summary is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.

All abbreviations except for SI symbols should be written in full the first time they appear. Generic or clinical names should be used for all compounds: materials and products should be identified. The species of any animals used should be stated precisely. Sources of unusual materials and chemicals, and the manufacturer and model of equipment should be indicated.

Materials and products should be identified in the text by the generic name followed by the trade name in brackets.

Reference Style. References should be quoted in the text as name and year within brackets and listed at the end of the paper alphabetically. All references must be complete and accurate. Online citations should include date of access. Use MedLine abbreviations for journal names. They can be found at: http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

Brown GM, Reichlin S. (1972). Psychologic and neural regulation of growth hormone secretion. *Br J Psychiatry* **34:** 45-61.

Cox T, Cox S. (1983). The role of adrenals on the psychophysiology of stress. In *Current Issues in Clinical Psychology,* Karas E. (ed). Plenum Press: London, 3-12.

Lazarus R. (1996). *Patterns of Adjustment.* McGraw-Hill: New York.

Illustrations. Supply each illustration on a separate sheet. Write the lead author's name and the figure number on the reverse, with the top of the figure clearly indicated. Supply original **photographs**; photocopies or previously printed material will not be used. Line artwork must be high-quality laser output (not photocopies). Tints are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Supply artwork at the intended size for printing. The artwork must be sized to the text width of 75 mm one column or 155 mm two columns.

Colour illustrations will not be accepted.

Copyright. To enable the publisher to disseminate the author's work to the fullest extent, the author must sign a Copyright Transfer Agreement, transferring copyright in the article from the author to the publisher, and submit the original signed agreement with the article presented for publication. A copy of the agreement to be used (which may be photocopied) can be found in the first issue of each volume of *Psycho-Oncology*. Copies may also be obtained from the journal editor or publisher, or may be printed from this website.

Further Information. Proofs will be sent to the author for checking. This stage is to be used only to correct errors that may have been introduced during the production process. Prompt return of the corrected proofs, preferably within two days of receipt, will minimise the risk of the paper being held over to a later issue. 25 complimentary offprints will be provided to the author who checked the proofs, unless otherwise indicated. Further offprints and copies of the journal may be ordered. There is no page charge to authors.

OBSERVER-RATED DISFIGUREMENT SCALE (Katz *et al.*, 2000)

Disfigurement may be defined as a visible and negative alteration in appearance resulting from disruption of the skin, soft tissues or bony structures.

The degree of disfigurement may be represented on a continuum ranging from minimal to severe.

Please rate each patient you see in terms of face and/or neck disfigurement on the nine-point rating scale provided in which "1" refers to minimal disfigurement and "9" refers to severe disfigurement.

To assist you in making your rating, the following examples are provided:

Example of rating of "1"	Example of rating of "5"	Example of rating of "9"
Disfigured area/scar small in size Shape of face/neck not distorted Facial expression not affected Disfigurement minimally visible (i.e. at close range only)	Disfigured area/scar moderate in size Shape of face/neck somewhat distorted Facial expression somewhat affected Disfigurement moderately visible	Disfigured area/scar large in size Shape of face/neck very distorted Facial expression very affected Disfigurement very visible (i.e. visible from afar)

Rating scale:

Minimal disfigurement Severe disfigurement

1 2 3 4 5 6 7 8 9

APPENDIX 3

Major Research Project proposal

		Pages
3.1	Participant Information Sheet.	**144**
3.2	Participant Consent Form.	**145**
3.3	Appearance Schemas Inventory (ASI).	**146**
3.4	Appearance Schemas Inventory-face (ASI-face).	**147**
3.5	Body Image Ideals Questionnaire (BIQ).	**148-151**
3.6	Body Image Ideals Questionnaire-face (BIQ-face).	**152-153**
3.7	Standard instructions for PRISM and PRISM+.	**154-155**
3.8	Clinician-rated Facial Appearance change scale.	**156**
3.9	Letter confirming ethical approval.	**157-158**

THIS SHEET HAS BEEN APPROVED BY THE WEST ETHICS COMMITTEE

INFORMATION SHEET FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

Brief Title of Project:

The importance of facial appearance in patients with eye cancer

You have been invited to participate in a study being carried out by the Department of Psychological Medicine at the University of Glasgow. The main aim of this study is to understand more about how a person's body image (i.e. perceptions, thoughts, feelings and actions about the way one looks) is affected by having experienced eye cancer. In addition we are interested in how people who have experienced other eye diseases (specifically thyroid eye disease) or no eye disease differ in terms of their body image to people who have had eye cancer.

Purpose of Study

There is currently little known about the effects of having eye disease on a person's body image. The aim of this study is to help us to understand more about how having a change in facial appearance affects different people in different ways.

Procedure

If you choose to participate in this study you will be asked to sign a consent form indicating that you have chosen to take part. You will then be asked to complete several questionnaires relating to body image.

(For eye disease patients):
You will also be asked to consider the relative importance of your eye disease and your facial appearance in your life.

The involvement in this study will take about 45 minutes to one hour of your time.

Your participation in this study may be of no direct benefit to you, but could help in the development of treatments for future patients. Your GP will be informed that you have taken part in the study, however, all information you give as part of this research will be confidential. If any of your responses indicate that your mood is very low or that you are very distressed your consultant will be notified. If you do not wish to participate in this study or you wish to withdraw at any time after commencing, your care will in no way be affected. If you want to discuss the research further or you have any questions which you would like answered then please contact: Ms Nicola Brown, Department of Psychological Medicine, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow; Tel: 0141 211 3920.

Thank you for your interest in the study.

WEST ETHICS COMMITTEE

FORM OF CONSENT FOR PATIENTS/VOLUNTEERS IN CLINICAL RESEARCH PROJECT

Title of Project:

The Importance of Facial Appearance in Patients with Eye Cancer

By signing this form you give consent to your participation in the project whose title is at the top of this page. You should have been given a copy of the patient information sheet approved by the West Ethics Committee to read and to keep. Even though you have agreed to take part in the research procedures you may withdraw this consent at any time without the need to explain why and without any prejudice to your care.

Consent:

I,.....
(PRINT)

Of.....
(Address)

Give my consent to the research procedures above, the nature, purpose and possible consequences of which have been described to me

By.....Ms Nicola Brown, Trainee Clinical Psychologist.....

I also consent to photographic material being used in this research and I understand that all attempts will be made to make this material anonymous (if published):
YES / NO (delete one)

Patient's signature.....Date.....

Doctor's signature.....

THE APPEARANCE SCHEMAS INVENTORY (Cash and Labarge, 1996)

Indicate your beliefs about the 14 items below using the 1 to 5 scale (write each rating in the space provided).

1 Strongly Disagree	2 Mostly Disagree	3 Neither Disagree nor Agree	4 Mostly Agree	5 Strongly Agree

	Score: 1 to 5
What I look like is an important part of who I am.	.....
What's wrong with my appearance is one of the first things that people will notice about me.	.....
One's outward physical appearance is a sign of the character of the inner person.	.....
If I could look just as I wish, my life would be much happier.	.....
If people knew how I really look, they would like me less.	.....
By controlling my appearance,	
I can control many of the social and emotional events in my life.	.....
My appearance is responsible for much of what has happened to me in my life.	.....
I should do whatever I can to always looks my best.	.....
Ageing will make me less attractive.	.....
For women: To be feminine, a woman must be as pretty as possible.	.....
For men: To be masculine, a man must be as handsome as possible.	.....
The media's messages in our society make it impossible for	
me to be satisfied with my appearance.	.....
The only way I could ever like my looks would be to change what I look like.	.....
Attractive people have it all.	.....
Homely people have a hard time finding happiness.	.....

THE APPEARANCE SCHEMAS INVENTORY - FACE

Indicate your beliefs about the 14 items below using the 1 to 5 scale (write each rating in the space provided).

1	2	3	4	5
Strongly Disagree	Mostly Disagree	Neither Disagree nor Agree	Mostly Agree	Strongly Agree

	Score: 1 to 5
1. What my eyes look like is an important part of who I am.	.....
2. What's wrong with my eyes is one of the first things that people will notice about me.	.....
3. One's outward physical appearance is a sign of the character of the inner person.	.....
4. If my eyes could look just as I wish, my life would be much happier.	.....
5. If people knew how my eyes really look, they would like me less.	.....
6. By controlling the appearance of my face, I can control many of the social and emotional events in my life.	.....
7. My facial appearance is responsible for much of what has happened to me in my life.	.....
8. I should do whatever I can to always make sure my face looks its best.	.....
9. Ageing will make my face less attractive.	.....
10. For women: To be feminine, a woman must be as pretty as possible.	.....
For men: To be masculine, a man must be as handsome as possible.	.....
11. The media's messages in our society make it impossible for me to be satisfied with my facial appearance.	.....
12. The only way I could ever like my face would be to change what I look like.	.....
13. Attractive people have it all.	.....
14. Homely people have a hard time finding happiness.	.....

THE BODY IMAGE IDEALS QUESTIONNAIRE (BIQ)
(Cash and Szymanski, 1995)

Each item on this questionnaire deals with a different physical characteristic. For each characteristic, think about how you would describe yourself as you actually are. Then think about how you wish you were. The difference between the two reveals how close you come to your personal ideal. In some instances, your looks may closely match your ideal. In other instances, they may differ considerably. On part A of each item, you will rate how much you resemble your personal physical ideal by **circling** the number on the 0 to 3 scale.

Your physical ideals may differ in how important they are to you, regardless of how close you come to having them. You may feel strongly that some ideals embody the way you want to look or to be. In other areas, your ideals may be less important to you. On part B of each item, rate how important your ideal is to you by **circling** the number on the 0 to 3 scale.

1. A. My ideal height is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal height?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

2. A. My ideal skin complexion is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal skin complexion?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

3. A. My ideal hair texture and thickness are:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal hair texture and thickness?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

4. A. My ideal facial features (eyes, nose, ears, facial shape) are:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you are your ideal facial features (eyes, nose, ears, facial shape)?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

5. A. My ideal muscle tone and definition is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal muscle tone and definition?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

6. A. My ideal body proportions are:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you are your ideal body proportions?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

7. A. My ideal weight is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal weight?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

8. A. My ideal chest size is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal chest size?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

9. A. My ideal physical strength is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal physical strength?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

10. A. My ideal physical co-ordination is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal physical co-ordination?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

11. A. My ideal overall physical appearance is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your overall ideal physical appearance?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

THE BODY IMAGE IDEALS QUESTIONNAIRE (FACE) – (BIQ-FACE)

Each item on this questionnaire deals with a different facial characteristic. For each characteristic, think about how you would describe yourself as you actually are. Then think about how you wish you were. The difference between the two reveals how close you come to your personal ideal. In some instances, your looks may closely match your ideal. In other instances, they may differ considerably. On part A of each item, you will rate how much you resemble your personal physical ideal by **circling** the number on the 0 to 3 scale.

Your facial ideals may differ in how important they are to you, regardless of how close you come to having them. You may feel strongly that some ideals embody the way you want to look or to be. In other areas, your ideals may be less important to you. On part B of each item, rate how important your ideal is to you by **circling** the number on the 0 to 3 scale.

1. A. My ideal facial features (eyes) are:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you are your ideal facial features (eyes)?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

2. A. My ideal facial feature (nose) is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal facial feature (nose)?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

3. A. My ideal facial features (ears) are:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you are your ideal facial features (ears)?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

4. A. My ideal facial shape is:

0	1	2	3
Exactly As I Am	Almost As I Am	Fairly Unlike Me	Very Unlike me

B. How important to you is your ideal facial shape?

0	1	2	3
Not Important	Somewhat Important	Moderately Important	Very Important

STANDARD INSTRUCTIONS FOR PRISM AND PRISM+

(Buchi and Sensky, 1999)

We would like to understand better how your illness [mention the illness] affects your life at the moment.

I'd like you to imagine that this white board represents your life as it is now.

The yellow disk in the bottom right corner represents your "self," and this red disk represents your illness.

Where would you put your illness – the red disk – in your life at the moment? [Hand red disk to patient]

(Most people have an intuitive idea of where to place the illness disk, but if someone does not appear to understand the above instructions, go to those below:)

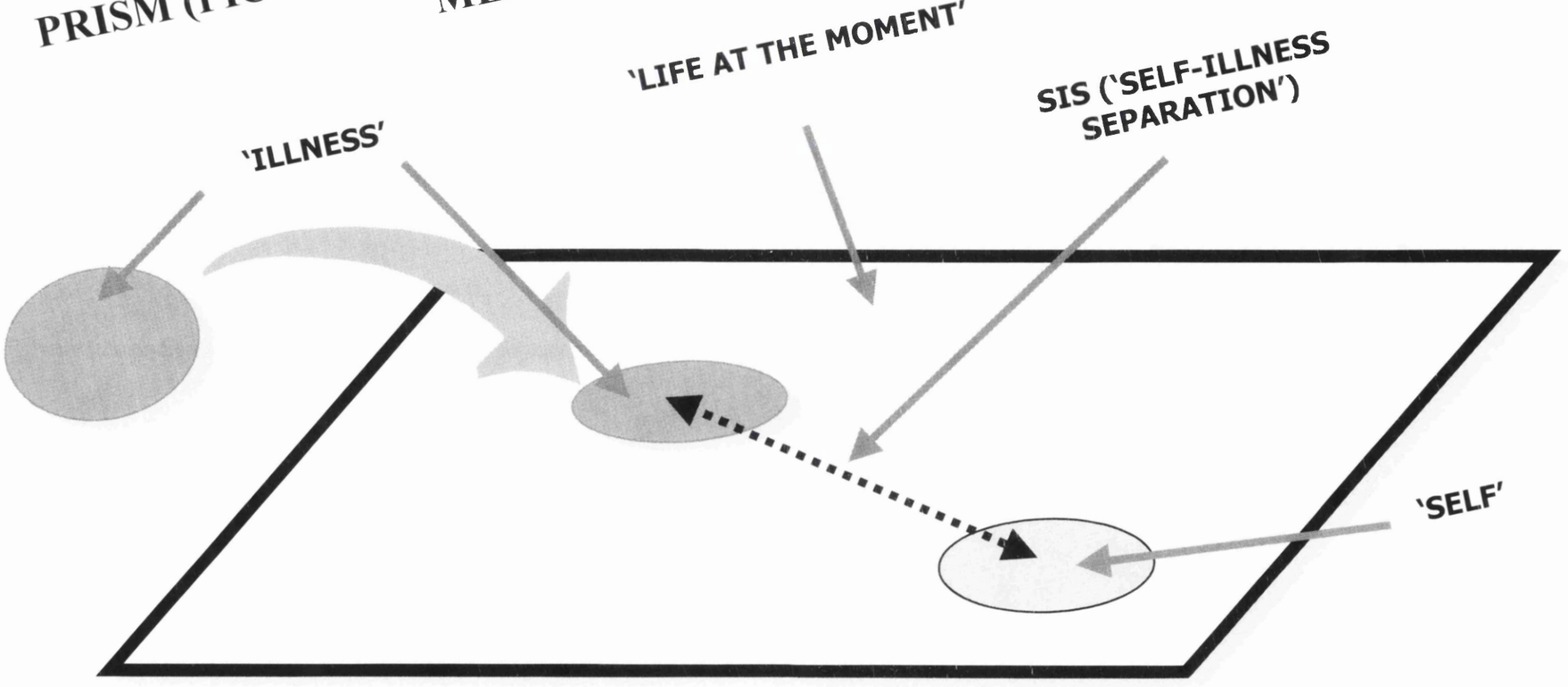
As this may be a rather unusual way of showing the place of your illness in your life, let me give you another example:

The blue disk represents your work or your job. For some people, work is an essential part of their lives and makes all the difference in how they see themselves. Such a person would put the "Work" disk on top of the "Self" disk [demonstrate this]. For other people, work is not that important. For example, they may work just to earn money. Such a person would place the "work" disk quite far from the "Self" disk [demonstrate].

Where would you put your illness – the red disk – in your life at the moment? [Hand red disk to patient]

(Measure the distance between the centres of the two disks – the Self-Illness Separation (SIS)).

PRISM (PICTORIAL REPRESENTATION OF ILLNESS AND SELF MEASURE) (Buchi and Sensky, 1999)



CLINICIAN-RATED FACIAL APPEARANCE CHANGE SCALE (Based on Katz *et al.*, 2000)

Facial appearance change may be defined as a visible alteration in appearance resulting from disruption of the skin, soft tissues or bony structures either directly or indirectly (e.g. following surgery) as a result of eye disease.

The degree of facial appearance change may be represented on a continuum ranging from minimal to severe.

Please rate each patient you see in terms of their facial appearance by **circling** the appropriate rating on the nine-point rating scale provided below in which "1" refers to minimal facial appearance change and "9" refers to severe appearance change.

To assist you in making your rating, the following examples are provided:

Example of rating of "1"	Example of rating of "5"	Example of rating of "9"
Changed area/scar small in size Shape of face not distorted Facial expression not affected Appearance change minimally visible (i.e. at close range only)	Change area/scar moderate in size Shape of face somewhat distorted Facial expression somewhat affected Appearance change moderately visible	Change area/scar large in size Shape of face very distorted Facial expression very affected Appearance change very visible (i.e. visible from afar)

Rating scale:

Minimal facial appearance change — Severe facial appearance change

1 2 3 4 5 6 7 8 9

West Glasgow Hospitals

OF THE NORTH GLASGOW UNIVERSITY HOSPITALS NHS TRUST

WEST ETHICS COMMITTEE
Western Infirmary
Dumbarton Road
Glasgow G11 6NT

Direct Line: 211 6238
Fax: 211 1920

Our Ref: AHT

Your Ref:

Please reply to: Mrs A H Torrie
SECRETARY - WEST ETHICS COMMITTEE

26 July, 2001

Miss Nicola Brown
Trainee Clinical Psychologist
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12

Dear Miss Brown,

01/106(2) Nicola Brown et al – The importance of facial appearance in patients with eye cancer.

The Committee at the meeting held on Tuesday 24 July, 2001, discussed the above study and approved both the study design and P.I.S. The Committee require a sentence added to the Patient Information Sheet in respect of the patient's GP being informed of their taking part in the study. This minor amendment should come back to me for filing. This study was given full approval.

Please note that the approval contained in this letter is valid for all sites which form part of the North Glasgow Trust. If however, this research is to be carried out at sights within the North Glasgow Trust other than the one covered by this letter, then a covering letter signed by the person responsible for the research on that site should be sent listing names, titles and addresses of all collaborating researchers. A copy of this approval letter should also be passed to them.

It should be noted that although Ethics Committee approval has been granted, Trust Management approval is still required. This should be obtained through the Research & Development Office at Gartnavel General Hospital (Miss W Burton tel No. 0115).

Due to the large volume of trivial and expected Serious Adverse Events (SAEs) being reported to the Committee, the Committee has taken the decision that they only wish to review SAEs where they are **serious and unexpected and where the investigator believes them to be unusual for the study under consideration.**

In situations where the study has a Data Monitoring Committee, then the Ethics Committee would only require sight of the summarised data at regular intervals of 6 months rather than individual reports.

In respect of MREC approved studies, only events which fall into the above categories and have occured at our local site should be passed to the Committee. All other events should be reviewed by MREC and should not come before this Committee.

The Committee would like to remind investigators that a copy of the Patient Information Sheet and Consent Form should be given to patient/volunteers for retaining.

This Committee conforms to and abides by the ICH Guideline for Good Clinical Practice.

Kind regards.

Yours sincerely,

Andrea H Torrie
SECRETARY - WEST ETHICS COMMITTEE

APPENDIX 4

Major Research Project Paper

		Pages
4.1	Copy of Information for Contributors to *Psycho-Oncology.*	**160-161**
4.2	Means and standard deviations for the Appearance Schemas Inventory (ASI) and the Body Image Ideals Questionnaire (BIQ).	**162**

Instructions to Authors

Initial Manuscript Submission. Authors in North America should submit four copies of the manuscript (including copies of tables and illustrations) to Dr Jimmie C. Holland, Memorial Sloan-Kettering Cancer Center, 1275 York Avenue, New York 10021, USA. All other manuscripts should be submitted to Dr Maggie Watson, Department of Psychological Medicine, The Royal Marsden Hospital, Downs Road, Sutton, Surrey, SM2 5PT, UK.

Authors **must** also supply:

- an electronic copy of the final version (see section below),
- a Copyright Transfer Agreement with original signature(s) - without this we are unable to accept the submission, and
- permission grants - if the manuscript contains extracts, including illustrations, from other copyright works (including material from on-line or intranet sources) it is the author's responsibility to obtain written permission from the owners of the publishing rights to reproduce such extracts using the Wiley Permission Request Form. Permission grants should be submitted with the manuscript.

Submitted manuscripts should not have been previously published and should not be submitted for publication elsewhere while they are under consideration by Wiley. Submitted material will not be returned to the author unless specifically requested.

Electronic submission. The electronic copy of the final, revised manuscript must be sent to the Editor **together with** the paper copy. Disks should be PC or Mac formatted; write on the disk the software package used, the name of the author and the name of the journal. We are able to use most word processing packages, but prefer Word or WordPerfect

Illustrations must be submitted in electronic format where possible. Save each figure as a separate file, in **TIFF** or **EPS** format preferably, and include the source file. Write on the disk the software package used to create them; we favour dedicated illustration packages over tools such as Excel or Powerpoint.

Manuscript Style. The language of the journal is English. All submissions including book reviews must have a title, be printed on one side of the paper, be double-line spaced and have a margin of 3cm all round. Illustrations and tables must be printed on separate sheets, and not be incorporated into the text.

- The **title page** must list the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)**.

Supply a summary of up to 200 words for all articles [except book reviews]. A summary is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.

All abbreviations except for SI symbols should be written in full the first time they appear. Generic or clinical names should be used for all compounds: materials and products should be identified. The species of any animals used should be stated precisely. Sources of unusual materials and chemicals, and the manufacturer and model of equipment should be indicated.

Materials and products should be identified in the text by the generic name followed by the trade name in brackets.

Reference Style. References should be quoted in the text as name and year within brackets and listed at the end of the paper alphabetically. All references must be complete and accurate. Online citations should include date of access. Use MedLine abbreviations for journal names. They can be found at: http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

Brown GM, Reichlin S. 1972. Psychologic and neural regulation of growth hormone secretion. *BR J Psychiatry* **34:** 45-61.

Cox T, Cox S. 1983. The role of adrenals on the psychophysiology of stress. In *Current Issues in Clinical Psychology,* Karas E. (ed). Plenum Press: London, 3-12.

Lazarus R. *Patterns of Adjustment.*McGraw-Hill: New York, 1976

Illustrations. Supply each illustration on a separate sheet. Write the lead author's name and the figure number on the reverse, with the top of the figure clearly indicated. Supply original **photographs**; photocopies or previously printed material will not be used. Line artwork must be high-quality laser output (not photocopies). Tints are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Supply artwork at the intended size for printing. The artwork must be sized to the text width of 75 mm one column or 155 mm two columns.

Colour illustrations will not be accepted.

Copyright. To enable the publisher to disseminate the author's work to the fullest extent, the author must sign a Copyright Transfer Agreement, transferring copyright in the article from the author to the publisher, and submit the original signed agreement with the article presented for publication. A copy of the agreement to be used (which may be photocopied) can be found in the first issue of each volume of *Psycho-Oncology*. Copies may also be obtained from the journal editor or publisher, or may be printed from this website.

Further Information. Proofs will be sent to the author for checking. This stage is to be used only to correct errors that may have been introduced during the production process. Prompt return of the corrected proofs, preferably within two days of receipt, will minimise the risk of the paper being held over to a later issue. 25 complimentary offprints will be provided to the author who checked the proofs, unless otherwise indicated. Further offprints and copies of the journal may be ordered. There is no page charge to authors.

Means and standard deviations for the Appearance Schemas Inventory (ASI) for the participant sample (n= 163).

	Eye Cancer N=44	TED N=44	Control N=75
ASI mean	**2.63** *(0.76)*	**2.90** *(0.70)*	**2.44** *(0.53)*

Means are shown in **bold** and Standard Deviations are shown in brackets in *italics*.

Means and standard deviations for the Body Image Ideals Questionnaire (BIQ) for the participant sample (n= 163).

BIQ	Eye Cancer N=44	TED N=44	Control N=75
Mean discrepancy	**0.65** *(0.85)*	**0.87** *(0.72)*	**0.89** *(0.64)*
Mean Importance	**1.3** *(0.75)*	**1.60** *(0.72)*	**1.35** *(0.67)*
Weighted	**1.23** *(1.62)*	**2.16** *(1.68)*	**1.41** *(1.28)*

Means are shown in **bold** and Standard Deviations are shown in brackets in *italics*.